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ABSTRACT

This book aims to provide teenagers with chronic illnesses or disabilities with useful information, moral support, and understanding as they make the transition to adulthood. It points out that although individuals with disabilities may want and need others for support, they can still live independently and make choices in all areas of their lives. Several young adults share their experiences and views on managing their lives, focusing on emotional adjustment, healthy lifestyles, planning for the future, setting realistic goals, understanding the importance of good communication, knowing their legal and human rights and being a self advocate, and exploring the need for relationships and physical affection. Step-by-step suggestions for preparing for independent living are offered. These suggestions address health insurance, Supplemental Security Income, employment, housing, independent living skills, postsecondary education, and recreation. Chapter titles include: "Living Your Own Life: You Are the Expert," "Health Is More Than Medicine," "Thinking about the Future: Am I That Different?," "Feeling Invisible: Communicating Effectively," "What Are My Rights?," "Sharing Life: The Human Need for Love and Affection," and "The Journey Continues." An appendix lists State Medicaid agencies, State programs for children with special health needs, Parent Training and Information Centers, Centers for Independent Living, vocational rehabilitation programs, and client assistance projects. (JDD)

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Living your own Life

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A Handbook for Teenagers by Young People and Adults with Chronic Illness or Disabilities

PACER Center, Inc.

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Living your own Life

A Handbook for Teenagers by Young People and Adults with Chronic Illness or Disabilities

Prepared by:

Nicole Roberts

Kris Schoeller, Staff, Speak Up for Health Project

Ceci Shapland, Coordinator, Speak Up for Health Project

Paula Goldberg, PACER Co-director

Marge Goldberg, PACER Co-director

Layout Editor: Jamie Smith, PACER Center

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4826 Chicago Ave. S., Minneapolis, MN 55417

(612) 827-2966 Voice & TDD

Philip Adams

Shawn Williams

Dedication

PACER dedicates this book to the memory of Philip Adams and Shawn Williams, two young men who exemplified the meaning of self advocacy.

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Preface

It is natural to have mixed emotions at the thought of becoming independent, especially after having lived under the supervision and protection of parents an entire life. When it was time for me to consider leaving home, I was elated and scared. On one hand, I couldn't wait to make choices about my life. On the other hand, I knew there would be no one else to blame or take care of me if I made a mistake.

This book is to provide you not only with useful information as you make the transition to adulthood, but also with moral support and understanding. Several young adults with disabilities or chronic illnesses, including myself, will share our experiences and views on managing our lives. We will also explore how taking care of our physical health can have an impact on our emotions, employment, education, and relationships with family, friends and loved ones.

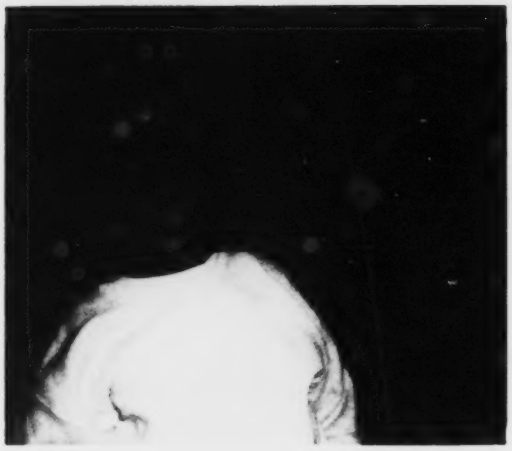
We hope to prove that although all of us may want and need others for support, especially if we are physically dependent, we can still live independently and make choices in all areas of our lives. We believe that independence is defined by our state of mind and action, rather than by our physical body.

The last half of this book includes step-by-step suggestions for how to prepare for independent living. It lists agencies and organizations you can contact and suggests questions you may want to ask.

We sincerely hope this book will help you feel more confident, informed and secure when you are ready to begin living your own life.

— Nicole Roberts

A Parent's Perspective



As a parent, I'm excited and a little anxious about this opportunity to tell you something about myself and my family. I would like to share my own struggle to assist Kelsey in her journey toward independence.

My name is Bev, and my daughter Kelsey is one of the teenagers you will read about in this book. Kelsey, almost 17, is the youngest in our family. She has two brothers, Chris, 25, and Pete, 18. Kelsey lives with her stepfather, Will, and me.

Looking back almost 16 years ago when Kelsey was first diagnosed with spinal muscular atrophy (SMA), I am aware of how far doctors have come in caring for children with chronic illnesses. I will never forget when Kelsey was 1 year old, and I had to bring her in for a painful test to see what was going on with her muscles. After a neurologist who we had never met before administered the test to Kelsey, he looked at me while he walked away and said bluntly, "There's something wrong with your daughter's nerve cells." I was so scared for the long week afterward while we waited for the conclusive test results.

Our worst fears were realized when another much kinder neurologist informed us that Kelsey had SMA and could die as early as age 5. Obviously since then we've seen that she can live a lot longer than expected. Ironically, although Kelsey has struggled with many hospitalizations, she has not had complications from SMA.

During Kelsey's early years, I was scared and angry. I was angry at everyone and anyone who appeared insensitive to Kelsey's disability. All during this time, however, I kept all this anger inside and walked around with a smile on my face because I wanted people to believe I was coping so well.

When Kelsey turned 5, we became a single-parent family. I struggled with trying to be a good mom to all my children. I was also coping with being a single person again. I tried to meet everyone's needs, including my own. Even though I had the best intentions, I know I wasn't always there for everyone.

It seems we are a family that is not at ease talking openly about our feelings, as I'm sure is true with other families. However, we are a family of survivors dealing with what comes our way with a quiet strength. This has worked.

It's been my experience that sometimes well intentioned medical and school professionals aren't always sensitive and therefore don't act in Kelsey's best interests. For this reason, I keep encouraging Kelsey to be assertive and express what she needs to the people who can make a difference in her life.

Of course, encouraging Kelsey to become independent means that I have to learn how to take a "backseat" and know when I should let go and allow Kelsey to deal with her own issues. I cannot know what it is like to live day to day with a disability, and I sometimes forget that Kelsey is the person who knows her needs best.

One of those needs is a personal care attendant, which has made an enormous difference in Kelsey's life. Kelsey has been fortunate to have had many dedicated, caring, fun-loving, responsible people who have allowed Kelsey to have the independence, companionship and freedom which is so necessary to all young people, especially those with disabilities. She has learned how to direct her own care, ask for what she needs, and, as a result, has become less dependent upon me.

On the one hand, this has given Kelsey's stepfather and me more freedom in our lives to do the things we enjoy, but at the same time I have to cope with feelings of rejection because I feel invisible now that Kelsey has her attendants and doesn't appear to want or need me.

Of course, I realize this is a natural need for separation that all young people go through with their parents. However, I found that because of Kelsey's previous dependence on me, it has been harder to separate from her than from my other children. I had always expected Kelsey to depend on me, and when I found that she didn't need me anymore and seemed not to want me around as much, it made me feel shut out and unimportant in her life.

As you may have guessed, I am a worrier like many mothers. But now, as the mother of three young adults, I know that the things I worried about usually didn't turn out as I feared they would. Many of my fears about Kelsey and her future now seem not so monumental. I am so proud of the person Kelsey has become. She has many friends, some of whom have disabilities also. She cares about others and their feelings, and she is a good listener. And importantly, she has set some goals for herself.

Kelsey is a high school junior, so together we're starting to plan for her college experience and for her to live on campus. There's a lot to plan, so we're realizing it's important to start early . Again, I'm the worrier wondering how it's all going to "shake out." But most of all, I'm excited about this important venture in Kelsey's life — her first big step toward independence.

I have often worried that Kelsey would always have to be dependent upon me, and I've been concerned about how that would affect, or possibly diminish, my own life and freedom. Although I feel guilty even having these concerns for my own independence, now I'm confident that Kelsey has the inner strength, skills and spirituality she needs to meet her life's ever-changing challenges on her own.

Thanks for this opportunity to tell you about Kelsey and myself. There will be exciting days ahead, and I wish for all of you the opportunity to work together with other people with disabilities. As a group, you can be powerful in helping yourselves and others to meet your needs and to know your rights so you may have a meaningful and satisfying life. Have an exciting journey.

Bev Benker

Introductions

Meet the people who will share their thoughts and feelings about their disabilities.

NICOLE, 22, lives in her own apartment with a friend who works full time as her attendant. Nicole is the narrator of this book. She is a writer and is working on a novel that would portray people with disabilities as "regular human beings." She has spinal muscular atrophy, a form of muscular dystrophy, and uses a power wheelchair.

DEBBIE, 23, lives with a friend and works full time as a supervisor for a youth employment program. She has a dream to start her own production company. Debbie has osteogenesis imperfecta, which is a genetic bone defect. She uses a power wheelchair.

TIM, 28, works as a computer programmer for the Department of Transportation and has plans for work advancement , a home and a family. He has cerebral palsy with spastic quadriplegia, which affects all four limbs and his speech. Tim uses a power wheelchair most of the time, but can use a walker to get around in his apartment.

KELSEY, 15, lives with her mother and step father and attends high school. She would definitely like to live on her own and attend college. Kelsey has spinal muscular atrophy, a genetic disease affecting all of her muscles. She uses a power wheelchair.

JULIE, 20, attends a community college and would like to attend a university to study special education and work with younger children. She would also like to have a husband and a family. Julie has spinal muscular atrophy. She uses a power wheelchair.

SUE, 21, has a job as a relay operator for persons who are deaf. She attends a university and is working toward a degree in psychology. She has blindness as a result of retinal detachment.

DEAN, 25, is married and has two step children. He works as a building engineer for medical clinics. Dean has juvenile onset type I diabetes.

MICHELE, 22, attends college and lives on her own with the help of a personal care attendant. She has juvenile rheumatoid arthritis and uses a wheelchair most of the time, but can walk short distances.

1

Living Your Own Life: You are the Expert

GOAL: To begin trusting that you are the expert on yourself.

One of the keys to being confident and successful in a life of independence is learning to trust ourselves and our perceptions of how our body is working and how we feel. It isn't always easy to trust ourselves enough to assert our opinions, especially if we have differing views than our parents or doctors. Nevertheless, being independent means having our own thoughts and feelings, and when it comes to our bodies, that means trusting that we are the experts.

Many people find it interesting and helpful to research and learn as much as possible about their particular disability. I have found that learning about my disability helps me be more confident in asserting myself when I have a physical or emotional problem related to my muscular dystrophy. I am more informed and can therefore explain my problems more easily, which allows others to understand and help me.

There are many ways we can learn about our disabilities. Take Debbie for example:

DEBBIE: The medical term for my disability is osteogenesis imperfecta. The layman's term is brittle bone disease. It's a genetic bone defect that my mother had and passed on to me. I learned about it gradually from my mom, just by living with it and attending meetings with groups of people with the same disease. But I learned the most my sophomore year in high school. In biology class, I chose my own disease for independent study because I thought it was a good opportunity to get a good grade and teach me about myself.

I know myself pretty well, now. I've gotten to know the signs of early respiratory problems, so I can usually go early and get antibiotics before things get bad.

At some point in our lives we may be confident enough to say:

DEBBIE: I know what I need to do and not to do to keep healthy. However, I don't always listen to myself.

Although we might not make the best decisions in some cases, the most important thing is that we know we aren't making the best decisions. In other words, we take responsibility for our actions.

In most states, when you turn 18, you are expected to make decisions and sign release forms for medical treatment. If you are unprepared, this can come as a shock to you and your parents, as you have become comfortable with your roles as parent or child. Suddenly, you legally become equals.

TIM: My doctors know I understand what I can and cannot do. They allow opportunities for me to make decisions. I have never had to fight for that with the doctors. I am more afraid of my mom than the doctors. Growing up, she was in charge. She almost seemed god-like. I thought she had that much power.

Most parents are, by nature, protective. That is why they may have a difficult time accepting us taking charge of our own life. They may be afraid we could be hurt. Mistakes, especially in health care, can have a large impact on our lives.

Taking time to communicate feelings, building trust by following medical treatments, and being respectful of each other's opinions can help make this time easier.

Kelsey has good ideas on how to prepare early for independence:

KELSEY: Being only 15, I still live at home with my parents. I know my body best, but I still have to learn a lot of things such as how to take care of myself, about health insurance, medical things, money and self confidence. My disease, muscular dystrophy, affects all of my muscles. It's progressive to some extent. I may get weaker. I can tell in my body when I am getting sick.

I don't feel that I'm real independent at age 15, but I've learned from my mom about doing a lot of things. I think it is important to start acquiring knowledge as soon as you can. You know that you will have to take care of yourself eventually, so you might as well start learning how to do things for yourself now. Then if you make a mistake, it's no big deal because you're still at home with support to deal with mistakes. But if you make a mistake when you're on your own, you've really made a mistake.

My mom is real supportive of me. I never feel uncomfortable asking her to do something. She never makes me feel that I'm a burden to her. The first time I took public transportation on my own, I knew she was worried. She worries, but it's not like she restricts me because of it.

I worry about handling my attendants on my own. If the attendants I have now don't do something right, my mom will always fix it later. When I'm on my own, she won't be there to fix it. If I would get sick and I was by myself, I would be more worried about being sick. I

would probably make myself sicker worrying about it. When I move the first time, I won't move that far away so I'll be able to come home.

Older friends with disabilities have helped me learn about accessible transportation and other things, such as what to expect in the future. When my friends and family can't help with my feelings, support groups are helpful.

We might fear that doing things our parents are worried about could damage our relationship with our parents. But sometimes our parents just need the opportunity to see that they can trust us.

JULIE: I think my parents thought that I would have some problems and that I would move back home. They mostly worried about safety. Now they know that I can take care of myself and make the right decisions in my life. I've been out and on my own for two and a half years, and I still have a good relationship with my parents.

Exercise

If you learn about your chronic illness or disability, it may help you feel more confident as the expert when it is time to take charge of your life. Below are some questions you might want to consider. Some of them we will explore later in this book.

- What are the causes and future prognosis of my chronic illness or disability?
- How do I reach a doctor in the middle of the night?
- What are my rights as a patient in the hospital?
- What do I know about health insurance?
- How does my disability affect my chances of getting a good job?
- Will there come a day when I will want to be married?
- Will my disability or illness affect my ability to have children?
- Does the medication I take have long term effects on my health?

2

Health is More than Medicine

Examining Different Aspects of a Disability or Chronic Illness

GOAL: To look at emotions in relation to living a healthy lifestyle with a disability or chronic illness.

SUE: Through the years, there has always been a lot of emotion tied in with my disability. Health care hasn't all been doctor appointments and medical terms. A person should never say that your disability is not a big deal and you should be over it by now. It's natural to be sad about it sometimes. Never underestimate the pain.

I think anyone who has any kind of physical problem or illness is bound to have emotions tied into it. Anger, fear, sadness, frustration, and a general feeling of powerlessness are some of the emotions many of us with a disability or chronic illness share.

I think anyone who has any kind of physical problem or illness is bound to have emotions tied into it.

DEBBIE: I expect my heart and lungs to give me more problems in the future; my joints, too. I already have some problem with my elbows. I haven't had any problems with my hearing so far. Because you have bones in your ears, often what happens is they basically deteriorate and lump into one piece. I would really be upset if I became deaf, I think, because I love music so much.

Some people with my disability don't make it into their 20s, but my mother lived to be 58, which they consider old. I hope I make it that long.

DEAN: In the summer of eighth grade, I decided not to get pushed around any more. I was a big kid, and one day I was going into an insulin reaction. There was this kid who always picked on me. I confronted him, and I didn't get teased again.

KELSEY: It definitely scares me that in the future I might get weaker.

Sometimes I find myself cursing, hating, fearing and resenting my body. I think to myself, "I want a different body, one that can walk and isn't in pain, or sick all the time. One that is strong and looks normal, not disabled."

As I've grown in life, I've begun to notice the physical and emotional effects of rejecting my body in this way. However, I can't force myself to "think positive" when I honestly don't feel positive. For me, the battle to "think positive" only creates more frustration and unhappiness. I can't get positive when I'm feeling sad, angry or frightened.

Lately, I have been learning that the most important positive thinking is simply being kind to myself. Being kind to myself means allowing myself to feel all emotions, good and bad, while at the same time being kind to my body. For example, although part of me may feel anger and even hatred at my body because it can't walk, there is another part of me

that knows my body is doing the best it can under the circumstances. In the same way, this other part of me knows how natural it is that I'm angry about not being able to walk, and so I don't need to feel guilty about feeling anger. Therefore, all parts of me are accepted and taken care of, rather than rejected and hated or feared.

Being kind and accepting of my disabilities, as well as strengths, helps me have understanding and kindness for others, who naturally also have strengths and weaknesses. I feel this understanding has made me a kinder person in general.

Many of us find that by helping ourselves cope we can gain a lot from our experience.

DEAN: I'm glad I have diabetes. It developed *me* into *me*. I am not discriminatory or controlling because I know what it is like to be discriminated against. Sometimes I was angry that I couldn't have a childhood and I couldn't fly helicopters, but that also made me wake up to what I did have. It turned into a kind of blessing. Having diabetes helped me to develop into someone I wouldn't have been.

Since health is more than medicine and doctors appointments, the effort to live a healthier lifestyle ends up very concretely affecting all areas of life. For example, to stay healthy I not only need to eat a healthy diet, rest when necessary, and make more effort to see the doctor for check-ups, but I also need to take care of business and other obligations. I need to avoid stress, try not to overextend myself socially, and stay away from people or places that make me feel bad emotionally or physically.

Of course, we can only do our best, and although this may sound easy, it's not. I don't always take care of myself as best I could; we all make mistakes. But perhaps the most important part of making a mistake is learning to forgive ourselves and move on. In order to be light-heartedly independent, I think we first need to accept that we will more than likely make plenty of mistakes!

DEBBIE: My mom let me make mistakes, and I'm glad that she did because every time you make a mistake, you learn something. If you fall down, you get back up again. You have to learn by making mistakes and goofing up every once in a while.

Exercise

Since health will affect all aspects of your life, it may be helpful to take a few minutes to think about school, employment opportunities, living arrangements, friendships, marriage, parenting, etc. How will your health affect these areas of your life?

3

Thinking About the Future: Am I That Different?

GOAL: To plan for the future and have realistic goals.

Sometimes it seems that having a disability is a separate species from being human — especially since we have often been treated so differently than people without disabilities. But, of course, we are only human, subject to the same emotions and similar life situations as everyone else.

DEAN: Adolescence is a time when you're going to be angry anyway. I think so much gets attached to the disability when it's just people are people.

A young woman recalls, "Adults expected me to live like a medical textbook, but I was more concerned with living like a teenager." (Chesler, 1987)

It is common for anyone between the ages of 10 and 18 to experience physical, emotional, psychological and social changes. Often people in this age group feel a need to belong to a group of friends, yet feel unique; to conform to peer pressure, yet set their own trend; to feel afraid at times, but also have a sense that nothing bad can happen; to want to be independent, but not yet have the self confidence to feel secure alone.

Many times breaking into our own life can cause tension between us and our family members and peers.

This is often the time to explore and learn how to become our own person. We no longer simply believe what our parents told us; we want our own beliefs and values. Many times breaking into our own life can cause tension in our relationships with family members and peers. This is understandable since most times of change are also, temporarily, times of turmoil.

Having a chronic illness or disability can increase the intensity of young adulthood. There can be added anger, frustration and fear. We have the same basic needs as anyone in this age group; however, we also have extra considerations and limits that may be placed on us as we work toward independence.

For me, one of the hardest things during my teenage years was that I wanted to challenge and defy my parents, as many teenagers do. However, because I was physically dependent on them for personal care, my desire for independence seemed thwarted. I couldn't run away from home or even stay in my room alone all day; it was obvious that my parents had considerable control over me because I needed so much of their help. This added extra pain for my parents and me during my teenage years. I couldn't simply break away from them, and they couldn't simply allow me to be alone.

There are many other special problems you may encounter that add to the difficulty of this transitional age. For example, if your chronic illness or disability is severe, you or your parents may think it futile to plan for the future. If your disability or chronic illness is hidden, it can seem easier to deny, hide or ignore the needs of your health.

DEBBIE: I feel that I have been fortunate because both of my parents have disabilities. My mom has osteogenesis

imperfecta and my dad had both his legs amputated. Because of their disabilities, I didn't get sheltered, at least not like a lot of other people with disabilities who have able-bodied parents. I find they often don't learn about themselves, or the disability, until they're 20 or beyond because they are taught to ignore it. No one ever talks about it because they think if you ignore it, it will go away. You are kind of brainwashed that you aren't different. Well, yes, you are different, and it's OK to be different.

Although we have the same emotions, desires and needs as everyone else when planning for the future, we must also take into consideration our different health needs and physical limitations. It might be useful to look at others and how they have achieved their goals, or are working toward their goals, while taking into account and accepting their different needs.

TIM: When I left high school, I really didn't have much direction in my life. I knew that I wanted to be married and have a decent life, but I didn't know how. Actually, my biggest fear was that some doctor would tell my parents that I belonged in a nursing home and I would stay there. I think my folks kind of expected that. But I went to school, and now I work as a computer programmer for the Department of Transportation. I live independently, and I don't need a personal care attendant. I do have a housekeeper.

MICHELE: You adapt and you live your life. You may have those obstacles, but you find ways to get around them if you really want to. At times things get hard, but you have to go through those things to make you realize what you're doing and to re-evaluate your priorities. I just think it's all a learning experience. I've taken all the things that

have happened, the good and the bad, and now I use the knowledge.

I had to learn the hard way, and I have. I took risks, and now I'm not afraid to ask for the things that I need.

I did have fears when I first moved out, but I didn't want to let my parents know that. I wanted them to think that I was making all the right decisions and I knew what I was doing when, in fact, I didn't. I learned like everyone else. I had to learn the hard way, and I have. I took risks, and now I'm not afraid to ask for the things that I need.

DEAN: My diabetes can affect my day-to-day life. I can get lethargic. That is one reason why I'm in the line of work that I'm in. I can pass the work off to tomorrow.

I think it's good to have big goals. Once I heard someone say, "Don't be afraid to make a mistake. Always reach for the sky. If you don't make it, at least you tried."

DEBBIE: My realistic dreams are to stay with youth work. My big dream, so to speak, is that I'd like to start a production company with a friend of mine. I'd like to get into music, because I know a lot of people in music. Not necessarily to have my own group, but be more involved in business. I'd also like to start a TV show, first on cable and then try to sell it in syndicate. It wouldn't be just about me, but about other people with disabilities and their lives. I want it to be about somebody who is really out there doing things, making a difference, having a real job, their own place. We all have to depend on someone at one time or another, but I want to show a person with a disability as being independent the way a lot of us are.

Obviously, you have to begin desiring something before you can begin finding the resources. In this way, sometimes just making a goal can help you obtain it.

DEAN: Kids really need to pick their own route and figure out what is important for their own independence.

There was an old guy who lived down the block, and one day he asked me what I wanted to be when I grew up. I was about 9 or 10. I said a fireman. He said, "That's really good, because most kids your age don't know what they want to be." That gave me a target, something to reach for. That had a lot to do with my independence.

DEBBIE: Coming to terms with your abilities and your disabilities is advice that I would give to young adults. I mean, accepting the fact that you can or cannot do certain things is O.K. Don't look at it as a negative, but turn it around and say while I can't do this, I can do that. Or the things that I can't do, I will contact this place or that person so that I can make it more comfortable for someone else to help me. Turn negatives into positives by finding alternatives.

Exercise

Take a DREAM walk. The purpose of this exercise is to help you give detail to your goals and to apply realistic thinking to the possibility of them coming true.

1. Picture the perfect place that you would like to be living in five or ten years. List all the things you see and the people who are there.
   - Do you have a job? If so, what kind?
   - Think about what the area looks like. Is it a forest, a city, a mountain or ocean?
   - What would you be doing for fun? Fishing, reading, listening to music, watching a movie, talking to a friend?
2. List your daily personal needs, health care needs and housekeeping needs. (For example, cooking, laundry, medication.)
   - Check the ones you think you could learn to do on your own.
   - What do you need help with? Brainstorm possibilities to get help and still live independently.

4

Feeling Invisible? Communicating Effectively

GOAL: To understand the importance of good communication.

Practicing good communication is vital to all aspects of our lives. We are nearly always interacting with other people — from family members and friends to strangers — whether we are talking, listening, using sign language or communication devices, touching, looking, writing, painting, or dancing. It's all communication.

Because we have disabilities or chronic illnesses, we are probably going to need help in certain areas of our lives. This means that we must not only be able to articulate our specific needs skillfully, but also be aware of the communications we are perceiving from the person or organization who is trying to help us.

DEAN: The biggest problem is people's lack of knowledge. People would stereotype me. Especially those who were in the "helping" role, such as teachers and service counselors. They would try to help me, but instead they would shoot me into the ground. They gave me the message that because I had diabetes, I couldn't do anything for myself. Then I would get angry and aggressive and want to "wake them up" to the truth.

Once I went to the superintendent of schools because the teacher refused to believe that there were times that my condition was bad enough to leave the room. There were lots of battles like these. I think when people are younger, they avoid the fights and don't try to inform the adults that are trying to help.

It is irrelevant whether the people who were trying to help Dean meant to "shoot him into the ground." What's important is Dean's perception of the messages these people were communicating to him. By sharing his feelings and asserting his needs, these people had the opportunity to change what they were doing so they could better serve Dean, or help him see how he had misunderstood their intentions. If Dean became angry but did not express his needs, these people probably would not understand what they could change to help him, and may have only become frustrated and angry at Dean.

It is by sharing our perceptions, feelings and needs that we become our own person — independent.

As you assume responsibility for your life, you will have to learn to take care of your health needs. This transition may seem hard at first, but most of us are glad to be in charge once we get used to handling the responsibility.

MICHELE: I didn't like to go to the doctor when I was a kid. I didn't like to wait, and the doctors didn't speak to me. They always spoke to my mom and dad about my health issues. I didn't even feel like I belonged in the doctor's office. I hated going. I mean, there was so much that made me feel belittled, less than. Sometimes they weren't very friendly, or they'd say one thing and end up doing another.

I wish doctors would understand that they need to make the child feel more a part of the situation. I felt at times that I knew more than the doctors, but I didn't say anything. Not that I didn't want to.

When I had to start taking responsibility, I didn't do it very well. I just didn't do it. I didn't have my priorities straight. Now I do. Since my health has become worse,

I have had to take responsibility. Nobody else is going to do it, and I really don't want anyone else to. Now that I live on my own, my mom and dad don't go with me to my appointments. I have to speak to the doctors myself. I have a good relationship with my doctor. We talk and I don't feel uncomfortable speaking about myself anymore. I just tell him everything.

If you have a doctor who doesn't listen, maybe you need a different doctor. *Or you need to speak to the doctor* and tell him or her that you don't feel that they listen to you. I mean, you're the patient, you live with the disease and you should know how your body's feeling. It's your body. I think the doctors should understand that.

Communicating with doctors can be hard for anyone. Part of the reason for this could be that visits with the doctor may include anxiety about hearing painful information, or undergoing painful procedures. Another reason could be that many people feel intimidated by doctors.

SUE: I thought that doctors always talked to me, even when I was younger. They explained things differently than they would now, but they did the best they could. I always felt that I was part of what was going on.

I wish all doctors would treat their patients like human beings. Sometimes I think that doctors forget that children are people and still know something about what's going on. I wish I could tell doctors to treat children with the same respect that they would treat an adult. I would tell children to ask questions if they have them. Depending on how young a person is, doctors can really be intimidating. If they act like they don't want to talk to you

and like you don't make a difference, what's going to give you the courage to ask questions?

I remember when I was younger, it was hard enough to ask questions, even though I was always treated with respect by my doctors. If a child's not treated with respect, there's nothing to give them the courage to ask questions. It helps if the parent treats a son or daughter as though they have intelligence and they're a person, because that can send a message to the doctor.

It can take courage for us to admit that we don't understand a doctor's complicated language or that we don't agree with what the doctor is saying. However, it is vital that we understand what doctors are telling us. We have to be brave and willing to admit when we don't understand, or disagree with what they are saying.

The truth is that doctors can be frightening for many people. Nevertheless, it may help to keep in mind that doctors are just human beings, and they don't have easy jobs. Sometimes they must tell people very scary information about their futures. In addition, our society places an almost God-like responsibility on doctors to be able to cure disease and fix human bodies. However, most doctors are aware of how limited their medical knowledge can be, and how, ultimately, no one can control how a disease affects our bodies.

Most doctors are aware of how limited their medical knowledge can be, and how, ultimately, no one can control how a disease affects our bodies.

I am better able to communicate my feelings and opinions to a doctor if I can see them simply as a fellow human being who is trying to help, rather than an enemy trying to make me do things I don't want to do.

Usually it takes one effort at a time before we begin to feel comfortable speaking up for ourselves. Each time we admit we don't understand, that we're afraid, or that we need help, it makes it easier for us to do it again the next time. Sometimes it helps practicing speaking up for ourselves with someone we trust to be supportive — like a friend or relative. But if you have a doctor that you just don't feel comfortable talking honestly to, it is your right and responsibility to find a new one.

TIM: If I didn't agree with my doctor, I would talk about it. He knows that in the end I'll do what I want to anyway. When I was younger I had several doctors who were "therapy happy." They haven't sent me to therapy in a long time, but if they did and I didn't want to go, I would just tell them no.

JULIE: Because I need help lifting out of my chair and getting dressed, I bring an attendant to the doctor's office for my appointments. The doctors usually talk to me, but I've been to get X-rays and the doctor's assistant talked to the person that brought me. At the pharmacy, the prescription was handed to the attendant, and I was referred to but not spoken to directly. Usually I laugh about it and let it go.

Occasionally, many of us are treated as though we are invisible. This can feel very insulting. That is why we need to let the people who ignore us see that we are in charge and able to take responsibility for ourselves. In a sense, it is our job to teach them how we want to be treated.

DEAN: I found a good doctor when I was 9, and I started to be more assertive. For young people who need a "jump start" to communicate assertively, I say they need to get mad and decide not to let people run all over them. I would encourage them to be upset and know their rights and to fight back.

My mom treated me like a baby; her big, yet little, boy. She used to call me at work to see if I took my shots. I would just tell her to leave me alone. Kids have to stand up for themselves. People will get hurt, but maybe they just need to do that in order to learn we can be in charge.

People tend to come across like monsters when they're feeling insignificant and small. Often when people are especially angry, mean, threatening, or scared, what's really happening is that their feelings are hurt and they don't feel appreciated or worthwhile. Their nastiness is their only

defense — an attempt to protect themselves. Therefore, in order to have communication and kindness in relationships, we need to allow everyone involved to express their emotions and know they've been understood and respected, regardless of whether we agree with them.

There are ways to make communication more respectful. Below are techniques you can practice to improve communication skills. However, because we have been communicating our whole lives, we might think we already know how to do it and these techniques may seem strange.

Yet, when I used these techniques in my life, it surprised me to see just how often people didn't understand what I thought I had told them. Often I assumed I knew what other people were telling me, but later found my assumptions to be quite wrong. I think everyone could benefit from working on their communication skills, and I encourage you to give the topic some attention in your life — strange as it might seem!

Listening

Listening is an essential part of communication. Although this may seem natural, each person listens from his or her perspective and often hears and remembers only small pieces of information. If the topic is emotional, listening can become distorted in order to deal with one's own emotions. Thinking about what to say next may make the listener pay less attention to what is being said. Using some simple techniques can eliminate these blocks.

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Paraphrasing

Repeat the information you hear in your own words. Use phrases such as, "I understand you to mean . . . ," or "What I think you're saying is . . . ." Common understanding not only helps with immediate listening and communication, but it also gives direction for future action.

Perception checks

Emotions are often part of communication. Having feelings acknowledged and validated allows communication to move to issues. If emotions appear to dominate a conversation, talk about them. If you sense that the person you are communicating with is giving a negative message through eye contact, facial expression or body language, stop and ask.

Always speak from your feelings and without judgment. Use phrases such as, "It seems to me that you're frustrated," or "I sense from your frowns that I'm not being clear or I'm confusing you."

These tools can be practiced and become part of natural communication.

Exercises

Begin to acquire knowledge. It is a good idea to start a folder with medical information. Usually parents keep some records of medications, test results, doctors' names and other information. Begin to transfer the information to your folder.

Some things to remember when going to a doctor's appointment:

Before a doctor's appointment:

- Make sure the building is accessible, request an interpreter, or convey other specific needs.
- Write down questions and issues ahead of time to make sure nothing is forgotten.
- Always talk about how much time may be needed with the doctor. Arrange for extra appointment time if needed.

During the doctor's appointment:

- Write down information, if possible.
- ASK QUESTIONS IF YOU HAVE THEM.
- Talk about jobs, school or social time when appropriate so that the doctor receives a picture of your whole person.
- Know your right to refuse treatment if you believe it is unnecessary or repetitive, or has a high risk for serious side effects. Choice is a major piece of empowerment and of high self esteem.
- Consider asking for privacy to ask questions regarding love, marriage, sex, contraception and more.

After the appointment:

- Follow the prescribed treatment. If you have questions about medication or treatment, call the doctor right away to discuss your concerns.

5

What are My Rights?

GOAL: To know your legal and human rights and be a self advocate.

In order to live independently, we have to learn to stand up for our desires and beliefs. This is often referred to as self advocacy. Being our own advocate means that we have the power and responsibility to communicate our rights and needs to others.

The ability to be our own advocate depends on a belief that we are worthy of support. This is often the hard part for many people with disabilities or chronic illness because our society tends to put up barriers that exaggerate differences or handicaps.

MICHELE: Sometimes I feel that I'm not being listened to because I'm in a wheelchair. People assume because I'm in a chair that I probably can't speak for myself. But usually when I do speak, I blow people away. Sometimes I get really sick of people thinking that I can't speak just because I'm in a chair, but then I don't think it's my responsibility. I used to care a lot about what people thought about me, but I know that I won't be happy thinking that way. If the people are of any importance in my life, then it may matter to me what they think. But usually they are not important and so I can just forget it.

People assume because I'm in a chair that I probably can't speak for myself. But usually when I do speak, I blow people away.

TIM: The barriers for me are in other people's attitudes. Most people's attitude about people with disabilities is one of "don't bother them and they won't bother you." The majority of the population doesn't do that intentionally. It's just so ingrained in society.

Living in this kind of world makes being our own advocate crucial, but also difficult. We first have to work to accept ourselves and our differences before we can expect acceptance from others. However, our own acceptance is usually a life-long, gradual process. So although we are still insecure, we may find ourselves forced to assert our needs in a world that seems quite against us.

Luckily, being a self advocate doesn't mean we have to do it alone, but instead that we have to find others who can help us. Support can come from self advocacy organizations, independent living centers, government agencies and school counselors. (See list of resources in the appendix.)

As you are probably aware from personal experience, sometimes people with disabilities are denied basic rights.

DEBBIE: From the time of preschool to 4th grade and then partially through 6th grade, I was in a segregated class. In 7th grade I was just thrown into a mainstream school with no preparation at all and I didn't do that well. It's not that I wasn't smart or didn't have the ability to learn basic skills, but if you don't learn these skills in the first, second and third grades, then it's going to be almost impossible to function later in life.

I remember in third grade, I had to beg my teacher to teach me how to write in cursive. There was one other student and myself who had to beg the teacher to teach us cursive. It was because we were the only ones in the class who had the motor skills to do it. So because of other people's

more severe disability, we were going to be deprived of that skill. We had a right to learn and we shouldn't have had to ask.

This kind of treatment can further diminish our ability to have confidence in ourselves. Fortunately, this is becoming less and less acceptable in our society. We now have laws that can help us protect ourselves.

In 1975, **P.L. 94-142, Education for the Handicapped Act**, was passed. The law required schools to provide a free and appropriate education to all children, no matter how severe the disability, and it must be in the "least restrictive environment." This is to ensure that students with disabilities are educated with children who do not have disabilities. Today the law is known as the Individuals with Disabilities Education Act (IDEA).

This law requires that the school and your parents write an individual education plan (IEP) that is based on your needs and strengths and that you be invited to attend and contribute to the meetings. The goal of the school and other agency personnel is to assist all students to become capable of independent living when they are adults.

The **Americans with Disabilities Act (ADA)** was passed in 1990. It is the single most important law for people with disabilities, mandating job opportunities and accessible recreation, transportation and leisure options (restaurants, hotels, theaters, hospitals, museums, etc.). The law is so new that many people are not aware of its provisions. There are ADA training sessions being held across the country to explain the ADA.

Another law that ensures basic rights is the **Rehabilitation Act of 1973**, Section 504. It prohibits discrimination against persons with disabilities from any federally funded programs, such as schools, job training programs, colleges, housing programs and more.

In addition, the **Rehabilitation Act Amendments** promote full inclusion and integration in employment, independent living, and economic self sufficiency for people with disabilities. A key point in these amendments relates to "transition services," which means a coordinated set of activities for a student, designed within an outcome-oriented process that promotes transition from school to post-secondary education, vocational training, employment, etc.

All of these laws are tools we can use to make sure we are allowed our rights. However, it is our responsibility to know the laws and ensure that they are followed. This is why it is important that we know how to communicate and advocate for ourselves.

MICHELE: I'm not afraid to ask questions anymore. I have a right to know the answers. I've found that for myself, I'm going to have to be assertive and advocate for the things that I need or I won't get them.

It is especially important to advocate for ourselves when it comes to doctors and medical treatments. After all, what is more important in our lives than our own bodies?

The first time you speak assertively on your own behalf or call the Office of Civil Rights to file a complaint about non-compliance to the ADA, you may be nervous about what others will think. However, for most of us these things get easier with time and experience.

TIM: For people who are deciding to be more independent, I would say don't let fear stop you. Fear is part of everyday life, but that does not mean that fear should be avoided. It means that what you are doing is important and that maybe you should be careful. Trust your instincts. People will tell you everything that they think, but you know what is right for you.

It is especially important to advocate for ourselves when it comes to doctors and medical treatments. After all, what is more important in our lives than our own bodies?

DEBBIE: I know I have rights with my doctor and with my treatments. For example, they were thinking of trying to straighten out my spine because my curve is sort of bad, but I opted not to. I was afraid that I may not live through the surgery, and I may end up less mobile and with less ability. They most likely would have had to put a rod in my back. I would have been in a brace or in a cast or something. I wouldn't have known if when I got out of it I'd have the strength or the ability to move

around the way I do now. I know it's true that it would [illegible]e the stress off of my organs, especially my lungs, but I've made it this long. If it's not broken, don't fix it.

DEAN: I don't always do all the things that the doctor suggests. I drink diet and non diet pop, and I just decide based on my body.

I think two of the best ways to build confidence is by first acquiring knowledge and then asserting your needs. If you are knowledgeable about your disability or chronic illness, you will naturally become more confident talking to doctors. If you understand the laws protecting people with disabilities, you will be more confident ensuring they are followed.

JULIE: Prepare yourself for independence. Have a good attitude about being independent, such as: I'm going to do it, I can do it and then do it. I love being independent. But you must be prepared and really know about everything you have to do such as paying the bills and grocery shopping. You are on your own. Period. Move on and be strong.

6

Sharing Life: The Human Need for Love and Affection

GOAL: To explore our need for relationships and physical affection.

Sexuality is more than just "having sex;" it's about sharing a relationship, holding a hand, smiling at someone across the room. It is about human contact, affection, and, many times (but not always), touch.

Unfortunately, talking about sex honestly is taboo, and it becomes even more taboo when you add a person with a disability into the picture. Much of our society still cannot imagine a person with a physical disability participating in, or even desiring, sex.

DEBBIE: I guess I never realized how much people look at us as non-sexual. It bugs me the way people ask questions. I really wanted to buy this T-shirt that said, "Able, but Unwilling."

Most parents are, by nature, protective. That is why they may have a difficult time accepting us being in charge of our own life.

It can be very lonesome and painful to live in a world where our basic need for love and affection is discounted simply because we have different bodies.

DEAN: I remember I felt inferior as far as sexuality and dating were concerned. If the girls knew about my diabetes, they wouldn't go out with me. It was hard to hide diabetes in high school because I had to go to the nurse's office so often. So I just didn't ask the girls out.

Even parents often neglect discussing sexual relationships with their children. This could be because of society's general embarrassment about sex, but many of us feel it also has to do with our disabilities or chronic illness.

Some doctors, in addition to not discussing sexual relations, may also not discuss safe-sex or proper health habits when it comes to our genital area. Although it may seem embarrassing, it is very important that we are seen for regular check ups, and that we talk to a doctor if we suspect any problems with our private parts. If for any reason we feel a doctor is uncomfortable talking with us about sex related topics or problems in our genital area, it is our right and responsibility to find a new doctor.

It's perfectly natural that we have sexual feelings; however, it is understandable that we may be ashamed or embarrassed about our feelings, especially given society's view that people with disabilities or chronic illness are, and should be, asexual.

TIM: As far as talking to my doctors about marriage and sexuality the topic didn't come up much. I suppose they really did avoid it. I didn't understand the changes my body was going through when I was in high school. I think that doctors would have looked at me cross-eyed if I'd have asked about it.

DEBBIE: My parents joked with me about sex, like, "When are you going to have a boyfriend?" But never was it directed at something real. It shocked me and upset me when my father made a comment about not getting pregnant and to protect myself.

KELSEY: My doctor and parents avoid talking to me about sexuality, but I don't think that it's because of my disability. They just don't want to talk about it. I could probably ask my mom some things, but I'm sure she would not initiate the conversation.

We have to remember that our parents have grown up in a society where the word "sexy" means a healthy, strong, able-bodied man or woman. This could be why our parents might think it's impossible for us to ever have a sexual relationship, since we have a disability or chronic illness. Likewise, if our chronic illness or disability makes us physically vulnerable, our parents might fear that we could be taken advantage of and hurt more easily than a person who is abled bodied.

Yet, no matter what anyone tells us or thinks about us, the truth remains: all people want, need and are capable of giving and receiving love.

It could be these and other fears combined that cause parents to simply choose to avoid the topic of sexuality with us. It's very sad, because although I do not think this is a good decision on a parent's part, it is nevertheless unmistakable that they are acting out of their pain and sorrow for us. They want us to be happy, but they're afraid we may never have a love relationship.

Yet, no matter what anyone tells us or thinks about us, and regardless of societal taboos, the truth remains: all people want, need and are capable of giving and receiving love.

DEBBIE: The positive things about being married would be having someone to be with; someone you can trust, spend time with, share simple things with like your daily routine. It would also give you the physical contact that everyone needs like hugging and cuddling, and just having someone as a friend and companion.

JULIE: When I think about marriage, I imagine myself in a relationship kind of like my parents' relationship. They have a good, healthy relationship. They talk, they laugh, they have fun together. They have lots of friends and good kids. So I want to share my life with someone and have a good time. I want to be able to talk openly and share how we feel. I also want to be comfortably well off.

Many people have trouble finding a suitable partner for marriage or a long term relationship; having a disability or a chronic illness can make being in a relationship even more difficult.

KELSEY: I don't think of myself as having a sexual relationship until I'm married. At the same time, I don't really think of myself as someone who will get married, at least not now. It would be hard to find someone who is responsible and mature about things, like lifting me. My husband would be like my attendant in some respects. On the other hand, I do feel like I have something to offer another person. I think everyone does.

DEBBIE: I like being very social and seeing lots of different people, but I also like my time alone. So I guess if I was living with someone in an intimate way there would have to be some definite boundaries. They would have to understand that if I go away for a couple of hours, it has nothing to do with them. I just need time for me.

JULIE: Sometimes I think I could feel like I'm a burden to someone, or that I'm asking too much. When I'm married, I want my life and my profession, and I want him to have his life and his profession. I want my personal care attendant (PCA) to help me get up and ready in the morning. I don't want my husband to be my PCA. It would take the stress off to have my husband and my PCA separate.

TIM: I want to find the right mate. If I don't find anyone, I'll be okay. When I think about getting married, I think of someone to share everything with in my life. But I want to marry someone who doesn't expect me to take care of them. I also wonder what it would be like to have someone around when I want to be alone. Until you have flexibility taken away, you don't know what it will mean to you. Able bodied or disabled, it will take a special person for me to trust.

Because our society doesn't feel comfortable discussing sexuality, it may be entirely up to you to question your doctors about the effect of your disability or chronic illness on your sexuality. Also, you will need to find out about the possibility of passing your disability or chronic illness on to your children, and whether or not you are physically able to carry a child and give birth, or cause pregnancy.

Because our society doesn't feel comfortable discussing sexuality, it may be entirely up to you to question your doctors about the effect of your disability or chronic illness on your sexuality..

DEBBIE: I would like to have at least one biological child, but I don't know if I'm physically able. My mom did, but the disease is more severe in me and I'm smaller. Also, the curve in my back is much worse than hers was and so I don't know if I could physically carry a child. But if I can, I will, and I'd really like to.

I received a little bit of information from my doctor at the OB-GYN clinic. They gave me the name of a doctor that specializes in high-risk pregnancies. I didn't follow through with it because I was scared that they would tell me I couldn't have a baby. Until it comes up, and I have someone to be with, I'd rather not deal with it.

JULIE: I don't want my children to have muscular dystrophy, and I know there is a 50-50 chance, but I'm willing to take that chance.

KELSEY: I know that I probably cannot physically give birth. But if I could have a child and got pregnant and found out that it was going to have muscular dystrophy, it would perhaps be good to terminate. It would be very difficult because I wouldn't know how bad that child would have the disease, I mean with sickness and weakness.

DEAN: As far as having my own biological kids, I won't let diabetes stand in my way. I do want kids, and I won't feel guilty if one of them has diabetes. Millions of things can happen. Some will, some won't.

In addition to the physical health issues, when considering having children, there is also the issue of physically caring for a child.

JULIE: I would like to have a few children. A boy and a girl would be ideal. But there would be a problem in taking care of them. I think about that. Maybe I'll be the one to bring in the money and my husband would be home with the kids. Or else we would just have a nanny.

TIM: When I think about taking care of children, I think I can do at least as good a job as some parents out there. I know I wouldn't abandon them and I would try to do the right thing in all cases. But I don't know how easy it would be for me. I don't think that I could do it alone.

KELSEY: I don't think having children will be in my future because I don't know if I can deal with another person's trials and share my problems. But if I had a husband and I knew that he was willing to take on the responsibility of the care of the children and me, then I would love to have children.

Loving and caring relationships are an important part of life. Feeling comfortable with our own sexuality so we can communicate our needs is an essential part of becoming an adult.

The Journey Continues

Life can be complicated and difficult for a person with a disability or chronic illness. Not only do we have our physical issues to take into account, but we also have to deal with emotional pain and frustration caused by our society's unfamiliarity and lack of awareness about people with disabilities or chronic illnesses.

Much of the reason society is uncomfortable with us is simply due to the fact that people with disabilities and chronic illnesses have been kept out of the public's view for so long. Only recently has there been legislation to begin including us in society. Yet, despite these changes, some people still believe that people with disabilities and chronic illnesses are less cabable human beings.

It's our job to educate the public and correct societal beliefs. By simply living our own lives, and demanding equal access and treatment, we can make powerful changes in the attitudes of people. We need to firmly stand up for our legal, human and sexual rights.

We have the right to hold a job, attend school, communicate our opinions and express love and affection. We have the right to be equal human beings.

Resources

Step by step suggestions for young people moving to independence

What do you need to know about the services and resources available to you in your community?

In most states you will become a legal adult at age 18 and will be expected to make decisions, sign release forms for medical treatment and be your own guardian. Sometimes it comes as a surprise that suddenly you are responsible for decisions which you have very little information about. This section is included for you to learn who, where and what resources are available to you and how to become an "informed" decision maker about your future, understanding the supports that are available to you.

In the appendix we have listed the Parent Training and Information Centers for each state. They can provide information in many of the following areas.

■ Health care resources

This book was written as the nation's Health Care Reform Plan was being introduced. Despite the fact that the plan will not take effect for a year or more, learning about the plan and how it will affect you is important.

Obtaining medical insurance is a major concern for persons with chronic illness or disability. It is important to learn about health insurance because it may dictate where you live and where you work.

There are two types of health insurance — public and private. Private insurance can be purchased as an individual or through one's employer as a "group policy." This is the most common form of private insurance. Unfortunately, it is usually expensive and often will not cover people with disabilities or chronic illness. These are considered "pre-existing conditions." The best option as an adult is to go to work for a large company that has a group policy. They cannot discriminate against you.

If you qualify for public insurance or medical assistance, you can get health care coverage. The public system cannot turn you away. It is important to check with your state on the individual benefits. It is different in each state. To qualify for public insurance, your income must be very low.

Health insurance is very complicated and difficult to understand. Do not feel bad if you have difficulty with this information. However, it is important for you to be aware of how health insurance may affect your life.

Explore these insurance options and understand what will be covered and what will not. The first step is to find out at what age you lose coverage under your parents' insurance plan. You can do this by reading the insurance plan, calling your insurance agent or discussing the plan with your parents.

Private Plans

Option 1: If you turn 18 and enroll in college or a vocational school full time, you can continue on the family health policy until age 22 or 23.

Option 2: If you do not continue in school, you have the opportunity to stay on your parents' insurance policy through the COBRA continuation policy. (COBRA

Glossary of insurance-related terms

group plan
insurance obtained through an employer; family pays a portion of the premium

continuation
the ability to continue group coverage for a specified period of time when coverage would otherwise be terminated

preexisting condition
a health condition of an individual which existed before the individual became insured

premium
the monthly, quarterly, or annual charge one pays for insurance

prior authorization/ prior approval
approval for insurance coverage for a specific service that assures reimbursement for the service

waiting period
length of time a person must wait from date of employment or application for insurance coverage before the insurance plan goes into effect

stands for Consolidated Omnibus Reconciliation Act, a federal law for companies that have more than 20 employees.)

You must notify your parent's employer within 60 days of when you turn 18. COBRA will be available for three years. Under COBRA, you may continue on your family plan by purchasing the company's group plan. An advantage is that it does not exclude any pre-existing conditions. Any medical expenses that are a result of your chronic illness or disability will continue to be covered. The cost will be quite expensive; however, the cost will be less than a comparable health plan that is not at group rates.

Option 3: More than 30 states have a mandate that allows young adults to remain on a family policy if they are unable to obtain self-sustaining employment due to a physical or mental impairment. Contact your state insurance commissioner's office for that information. If it does, you must notify your parents' employers within 30 days of turning 18. This law does not apply to employers who are self insured.

Option 4: If you are attending college even part time, explore student health insurance. These plans are usually inexpensive (about $250 per year in 1988).

The plans usually have a pre-existing condition clause or a waiting period, up to one year, before they will pay for treatment of a preexisting condition. However, they cover other health needs during the waiting period and will provide coverage for the existing condition after the waiting period.

Option 5: Contact Blue Cross or a large health maintenance organization regarding their open enrollment period. Open enrollment may be offered continuously or periodically. This is a period when anyone can enroll for insurance and will not be denied due to a pre-existing condition. Open enrollment never denies coverage but it may limit coverage.

Option 6: High-risk insurance pools are available in several states. People are usually eligible if they can prove that they have been turned down by insurance companies or if the cost is too much for them to afford. These high-risk pools offer fairly good coverage, but they often have a clause for a waiting period for a pre-existing condition.

Public Plans

The following options are for persons using public insurance, often referred to as Medical Assistance or Medicaid.

Option 1: If your family has Medical Assistance or Medicaid, you will still be excluded from that coverage when you turn 18, whether you go on to post-secondary schools or not. However, some states have an option for coverage up to age 21. Contact your Medicaid office for information. (See Appendix for a list of state Medicaid offices.)

Option 2: Many young adults with chronic illness or disability who are eligible for Supplemental Security Income (SSI) are eligible for Medical Assistance in some states. Contact your Medicaid office to determine if you are covered.

SSI is a federal program that provides monthly cash payments to persons with disabilities and have little or no personal income or resources. This will be covered at length later in this section.

If these options are not available to you, explore local public health clinics and community agencies as options for routine health care.

State programs for Children with Special Health Care Needs

This is an option whether you have private or public insurance plans. These programs cover up to age 21 and often provide diagnostic services and reimbursement for inpatient and outpatient treatment. Some may pay insurance premiums, deductibles and co-payments for eligible individuals. For further information, contact your state program. (See appendix for a list of the programs.)

Filing complaints or appealing a decision

If you disagree with the policies of your private insurance company, such as when it refuses to cover treatment or equipment, you have a right to file a grievance and appeal. Doing your homework and being prepared and persistent are keys to getting what you need. Here are several steps to follow.

1. Know the grievance procedure for your insurance company.
2. If denied, study your policy — the actual certificate — to understand the coverage you are entitled to. If you have trouble understanding it, ask the claims representative at your insurance company to explain it to you. If you belong to a group policy through employment, it is also important to notify your company about your concerns. They are interested in their employees receiving the benefits they are entitled to and getting what they are paying for.
3. If you feel that the policy supports your position, call the claims representative at your insurance company and state your case. Be sure to get the representative's name. Keep accurate notes on each call, including the dates and times of each conversation and the names of persons you spoke to. Keep copies of any letters sent.

   Ask the company to explain its action and where in the policy the action is supported. If you do not understand the explanation, keep asking questions and telling them your stand and reasons.

   If there is an agreement during the conversation, do not hang up until you have a clear understanding of what they will do next to resolve your concern. Write a letter to the company stating your understanding of what will take place.
4. If you cannot resolve your claim, talk to the supervisor. Ask to speak with the claims supervisor or the manager. You may want to ask about the company's claims review process and request a review.

   To prepare for the review, ask for help from your doctor or other health providers. Some individuals have included scientific articles showing certain treatments that have helped youth with a similar chronic illness or disability. All information strengthens your case.

   Appealing your insurance claim will give you the chance for review by people who have the authority to give you what you need.

5. You do not have to wait until your complaint has gone through the grievance procedure of your insurance company to get outside help. File a complaint with the office of the state insurance commissioner. Contact the office to learn how to file this complaint.

Appealing a claim with Medicaid

If you do not agree with a decision made by Medicaid, you can appeal. You will be notified of a denial of service by letter. This denial will include instructions on how to appeal.

You must appeal within 30 days after being denied. You can take up to 90 days if you have an adequate reason. (These are Minnesota guidelines; contact your state Medicaid office for guidelines.)

A hearing will be set up in your area. At the hearing, you can explain why you believe denial of coverage was wrong. You may represent yourself, or ask a friend, an attorney, or a relative to help you.

An appeals referee will hear and decide the case. You will receive the decision by mail, usually within a month of the hearing. If you are not satisfied with the decision, you have 30 days to appeal to the district court.

■ Supplemental Security Income

Becoming independent also means that you will have to support yourself with some type of income.

Supplemental Security Income (SSI) is a federal program that provides monthly cash payments to persons who have a disability and have little or no income or resources. A person can be employed or unemployed and be eligible for SSI. You can be considered for SSI no matter what your age or if you are married or single.

Information provided here is for persons 18 and older, in or out of school, who are single and who have disabilities other than blindness. Persons who are under 18, married, or who are blind can contact the Social Security office at 1-800-772-1213 for specific information.

Application

At the time you apply, you must have a physical or mental disability that prevents employment and is expected to last at least 12 months. Disability is also determined by the ability to do substantial, gainful activity. Substantial gainful activity is defined as making $500 gross income. If you make less than $500, you are considered to have a disability.

You cannot have more than $2,000 in resources and be eligible for SSI. Resources are things a person owns that can be turned into cash. Resources can be items such as savings and checking accounts, stocks and bonds, personal and household goods and life insurance. A car is not considered a resource if it is used for necessary daily activities or for transportation to work or regular medical treatment.

Also, you cannot have more than $454 gross in earned and unearned income in the month before you apply for SSI. (Monthly limits change annually.) Examples of earned income include wages, earnings from self employment and money received for work in a day training and habilitation center or other rehabilitation center. Some types of unearned income include Social Security and other public benefits, most food and shelter given in return for work, and interest payments.

Applying for SSI can be done by calling 1-800-772-1213. People at this number will assist in arranging an appointment with your local Social Security Office. SSI will want written information in the following areas:

- Proof of age
- Social Security number
- Pay slips or other papers showing income
- List of resources, eg., bank accounts
- Records of all living expenses
- All medical records, including some proof of your disability or chronic illness, i.e., a signed statement from a physician. Information should include how your disability affects your ability to find and keep a job.

If you do not think that you have all this information, you should still apply. The Social Security office may be able to help you get the necessary material.

Monthly SSI payments

Once you qualify for SSI you receive a monthly payment from the federal government. In 1993 the maximum SSI payment is:

- $434 a month for a single person who pays all living expenses;
- $289.34 for a single person who does not pay own expenses;
- $30 for a single person living in a setting where medicaid is paying for over half of the cost of care.

If you have income, the federal monthly SSI payment is reduced to take into account the amount of income and what deductions you can take. It is very important to keep all income and resource records, such as pay stubs and interest statements, and immediately report any increase or decrease in income to Social Security. Failure to do so can result in Social Security asking for money to be repaid or paying you in one large amount for money they owe you.

Work Incentives

PASS

Under a PLAN FOR ACHIEVING SELF SUPPORT (PASS), you can set aside income and/or resources for work goals, such as vocational training, education, purchase of work-related equipment or the start-up of a business. Social Security decides if a PASS is acceptable. You must apply for a PASS in writing and include a realistic work goal, a date for achieving this goal, a clear savings/spending plan, and a method of keeping track of the funds which are set aside. Social Security can help a person write a PASS. You can arrange a PASS before applying for SSI, which will help you qualify if your income and resources are above the SSI limits.

Impairment-related work expenses

Impairment-related work expenses (IRWEs) are the costs for services and items a person needs because of his/her disability in order to work. These costs can include services and equipment used to get to work, perform your job, and return home.

Some examples would be certain types of attendant care services, transportation costs, medical devices, work related equipment, modifications to your home, routine drugs and medical services. Such related services and items can be deducted even if they are also needed for non-work activities. The costs can only be deducted if you pay them and receive no reimbursement.

1619(a) and 1619(b)
Persons may make more than $500 per month and still receive SSI payments under program 1619(a). For every $1 a person earns, his or her monthly SSI check is reduced by 50 cents. Under program 1619(b), when the SSI check drops to zero, a person continues to be eligible for Medicaid or Medical Assistance as long as eligibility for SSI is maintained.

(In most states if you qualify for SSI, you will also qualify for Medicaid. It may be necessary to apply for SSI and Medicaid separately.)

■ Employment resources

The Division of Rehabilitation Services (DRS) is an agency that provides employment-related services for people with disabilities. In some states, the agency is known as the Department of Vocational Rehabilitation. DRS is a state agency that is divided into regions. Each region has its own counselors who will work with you on an individual basis.

In order to get DRS services, you must have a disability that will make it difficult for you to find or keep a job. You must also need assistance from DRS to become employed.

DRS counselors will need proof of your disability from the school or your physician or both. This will give them the reason of why it may be difficult for you to get a job.

Once you are considered eligible for DRS services, the counselor will act as a case manager and will prepare an Individually Written Rehabilitation Plan (IWRP). Services that can be provided through DRS include:

1. medical and psychological evaluations that determine the extent of your disability,
2. a vocational assessment to determine vocational strengths and needs and interests,
3. counseling to assist you to understand the types of employment that you may be successful at or post secondary education that you will need,
4. artificial appliances such as braces, hearing aids, augmentative communication devices and glasses that will increase your ability to work,

5. transportation and income maintenance during treatment and training,
6. arrangement and tuition for vocational training,
7. placement in a suitable job and follow-up assistance to make sure that you are suitable and safely employed,
8. supported employment.

Services that the IWRP includes should be based on individual need, and not on services that are available. You should be actively involved in writing your IWRP and have an updated copy. The IWRP should be reviewed yearly.

Federal law mandates that DRS counselors are a part of transition planning. High schools should provide a DRS counselor to be part of your transition planning team. If you do not have a counselor, ask for one. They can be helpful in identifying future work options or work with the school to pay for vocational services.

If DRS decides you are ineligible, you have a right to appeal that decision. In addition, you can appeal decisions about the kind or amount of services DRS offers. A statewide advocacy project called the Client Assistance Project (CAP) will help you get the services you need. CAP can represent you in an appeals process at no charge. (See appendix for list of CAP projects and DRS offices in each state.)

■ Housing resources

When you are ready to find your own place to live, you'll need one that is affordable and, if necessary, accessible.

There are many resources within each state to assist you in finding housing. It is important to make contact with one or more of these resources and to get on a waiting list early. In some cases the wait may be several years.

There are several subsidized or low-cost housing options for persons with disabilities. These options are funded by the Department of Housing and Urban Development. You may want to contact this department first. It is listed in the telephone book under Federal Government Agencies. Each of the housing options has rules about who qualifies.

Low income public housing has housing for persons with disabilities. Local Housing and Redevelopment Authorities (HRAs) control public housing. They may also be a resource for you and can also be found in the Government section of the phone book.

When a person qualifies, Section 8 Existing Housing helps pay the rent on housing on the open market. Each county has its own limit on how much money a person or family can make to qualify for rent assistance. You can apply for this program only at certain times. Local newspapers print this information, or you can call your local HRA to find out the dates.

The Centers for Independent Living also keep a current list and provide assistance for persons looking for housing. (See the Appendix for a list of Centers for Independent Living.)

Another option is to contact your local Parent Training and Information Center (listed in the appendix) for assistance.

■ Independent living skills resources

The Rehabilitation Act of 1973 requires that states provide independent living services. This has been done through centers that are located throughout the state. They are consumer driven, which means that a large percentage of their staff and boards are people with disabilities. Most centers throughout the country (see appendix for list) serve as advocates for persons with disabilities by providing support in:

Personal Care Attendant — you will receive assistance in learning how to find and educate your personal care attendant to meet your individual needs and style. A personal care attendant is someone who will assist you to live independently. This person can help with dressing, eating, and "on the job" needs. Centers for Independent Living list agencies that provide attendants or offer money to find and hire your own PCA.

Advocacy Services — the staff will inform you of your rights and ways to get your needs met, including how to be assertive.

Information and Referral — you can learn about personal attendant care, legal assistance, medical care, special equipment, housing, support needed for driving or other transportation needs, or any questions about living on your own.

Problem Solving Skills and Training — there are individual and group problem solving sessions that give the opportunity to experience solving problems and increase your ability to take a risk.

Peer Support — other people with disabilities are employed and volunteer as support and mentors for persons with similar disabilities.

Housing Referral — centers can tell you about low-cost (subsidized) housing or housing that is accessible (having wide doorways, ramps or elevators and more).

Adaptive Equipment — workers can help you decide if you need special tools or equipment that will make things easier to live on your own.

Goal Planning — you can receive on-going education in the areas of cooking, cleaning, shopping, financial planning, job finding, and more.

■ Post-secondary options for education

All post secondary schools, technical vocational colleges and other community colleges and universities that receive federal funds must provide the necessary supports for you to attend. To find out more about your local institution, call the specific school and ask for the Office of Disabilities. There are some that have been making better progress in accessibility and accommodation, and you will want to know what they are doing or are willing to do. Again, it is important for you to know your rights and to be assertive in getting what you need. Even those that do not receive federal dollars are responsible to provide support under the Americans with Disabilities Act (ADA).

■ Recreation and leisure resources

This is the area that is one of the most important in the lives of young people and yet has the least amount of outreach and opportunities. Knowing your rights under the ADA and feeling that whatever is happening in your community needs to be accessible may encourage you to become involved. Developing important friendships that occur during leisure time is an important part of your life. Centers for Independent Living often provide recreational opportunities. In addition, as a result of the Americans with Disabilities Act, community recreation centers will be more accessible.

Self advocacy is important and necessary to access resources. There is a growing number of self advocacy organizations for persons with disabilities around the country. When there are many voices, the message is stronger and positive changes more likely to happen. The Centers for Independent Living may be the best place to meet and organize with other young adults who have disabilities. You may even want to get an organized group together in your school or community center. Another option to consider is to become active in the local specific disability organizations, such as the United Cerebral Palsy Foundation or the American Diabetes Association. Having the opportunity to observe other young adults and adults who have been successful in gaining their independence and forming meaningful relationships can be powerful as you look at your own goals.

Appendix

State Medicaid Agencies

Alabama
2500 Fairlane Drive
Montgomery, AL 36130
(205) 277-2710, extension 200

Alaska
Division of Medical Assistance
Department of Health and Social Services
P.O. Box 110660
Juneau, AK 99811-0660
(907) 465-3355

Arizona
Health Care Cost Containment System
801 East Jefferson
Phoenix, AZ 85034
(602) 234-3655, extension 4053

Arkansas
Office of Long Term Care
Department of Human Services
P.O. Box 1437, Slot 400
Little Rock, AR 72203-1437
(501) 682-8487

California
Medical Care Services
Department of Health Services
714 P Street, Room 1253
Sacramento, CA 95814
(916) 657-1496

Colorado
Bureau of Health and Medical Services
Department of Social Services
1575 Sherman Street, 10th Floor
Denver, CO 80203-1714
(303) 866-5901

Connecticut
Medical Care Administration
Department of Income Maintenance
110 Bartholomew Avenue
Hartford, CT 06106
(203) 566-2934

Delaware
Department of Health and Social Services
Delaware State Hospital
1901 North Dupont Highway
New Castle, DE 19720
(302) 577-4400

District of Columbia
Office of Health Care Financing
D.C. Department of Human Services
2100 Martin Luther King Jr. Ave. SE
Suite 302
Washington, DC 20025
(202) 727-0735

Florida
Health and Rehabilitation Services
1317 Winewood Boulevard
Building 6, Room 233
Tallahassee, FL 32399-0700
(904) 488-3560

Georgia
Department of Medical Assisitance
Floyd Veterans Memorial Building
West Tower - 1220C
2 Martin Luther King Jr. Drive SE
Atlanta, GA 30334
(404) 656-4479

Hawaii
Health Care Administration Division
Department of Human Services
P.O. Box 339
Honolulu, HI 96809-0339
(808) 586-5392

Idaho
Medicaid Policy and Reimbursement
Department of Health and Welfare
450 West State Street, Second Floor
Boise, ID 83720-5450
(208) 334-5795

Illinois
Medical Operations
Illinois Department of Public Aid
201 South Grand Avenue East
Springfield, IL 62763-0001
(217) 782-2570

Indiana
Medicaid Policy and Planning
Family & Social Services Administration
402 W. Washington St., Room W341
P.O. Box 7083
Indianapolis, IN 46207-7083
(317) 233-4448

Iowa
Division of Medical Services
Department of Human Services
Hoover State Office Building, Fifth Floor
Des Moines, IA 50319
(515) 281-8794

Kansas
Medical Services
Social and Rehabilitation Services
Docking Office Building, Room 628-S
915 Harrison Street
Topeka, KS 66612
(913) 296-3981

Kentucky
Department of Medicaid Services
Third Floor
275 East Main Street
Frankfort, KY 40621
(502) 564-4321

Louisiana
Bureau of Health Services Financing
P.O. Box 91030
Baton Rouge, LA 70804-9030
(504) 342-3891

Maine
Bureau of Medical Services
Department of Human Services
State House Station 11
Augusta, ME 04333
(207) 289-2674

Maryland
Health Care Policy, Finance & Regulation
Health and Mental Hygiene
201 West Preston Street, Fifth Floor
Baltimore, MD 21201
(301) 225-6535

Massachusetts
Department of Public Welfare
600 Washington Street
Boston, MA 02111
(617) 348-5691

Michigan
Medical Services Administration
Department of Social Services
P.O. Box 30037
Lansing, MI 48909
(517) 335-5001

Minnesota
Health Care Administration
Department of Human Services
442 Lafayette Road, Sixth Floor
St. Paul, MN 55155-3848
(612) 296-2766

Mississippi
Division of Medicaid
Office of the Governor
Robert E. Lee Building, Room 801
239 N. Lamar Street
Jackson, MS 39201-1399
(601) 359-6050

Missouri
Division of Medical Services
Department of Social Services
P.O. Box 6500
Jefferson City, MO 65102
(314) 751-6922

Montana
Medicaid Services Division
Social and Rehabilitation Services
P.O. Box 4210
Helena, MT 59604
(406) 444-4540

Nebraska
Medical Services Division
Department of Social Services
301 Centennial Mall South, Fifth Floor
Lincoln, NE 68509
(402) 471-9147

Nevada
Welfare Division
Department of Human Resources
2527 North Carson Street
Carson City, NV 89710
(702) 687-4378

New Hampshire
Office of Medical Services
Division of Human Services
6 Hazen Drive
Concord, NH 03301-6521
(603) 271-4314

New Jersey
Medical Assistance and Health Services
Department of Human Services
CN-712-7 Quakerbridge Plaza
Trenton, NJ 08625
(609) 588-2600

New Mexico
Medical Assistance Division
Human Services Department
P.O. Box 2348
Santa Fe, NM 87504-2348
(505) 827-4315

New York
Division of Medical Assistance
State Department of Social Services
40 North Pearl Street
Albany, NY 12243
(518) 474-9132

North Carolina
Division of Medical Assistance
Department of Human Resources
1985 Umstead Drive
P.O. Box 29529
Raleigh, NC 27626-0529
(919) 733-2060

North Dakota
Medicaid Operations
Department of Human Services
State Capitol Building, Judicial Wing
600 East Boulevard Avenue
Bismarck, ND 58505-0261
(701) 224-2321

Ohio
Medicaid Administration
Department of Human Services
30 East Broad Street, 31st Floor
Columbus, OH 43266-0423
(614) 644-0140

Oklahoma
Division of Medical Services
Department of Human Services
P.O. Box 25352
Oklahoma City, OK 73125
(405) 557-2539

Oregon
Office of Medical Assistance Programs
Department of Human Resources
203 Public Service Building
Salem, OR 97310
(503) 378-2263

Pennsylvania
Secretary of Medical Assistance
Department of Public Welfare
Health and Welfare Building
Room 515, Box 2675
Harrisburg, PA 17105-2675
(717) 787-1870

Rhode Island
Division of Medical Services
Department of Human Services
600 New London Avenue
Cranston, RI 02920
(401) 464-3575

South Carolina
Health and Human Services
Finance Commission
P.O. Box 8206
Columbia, SC 29202-8206
(803) 253-6100

South Dakota
Medical Services
Department of Social Services
700 Governors Drive
Kneip Building
Pierre, SD 57501-2291
(605) 773-3495

Tennessee
Bureau of Medicaid
729 Church Street
Nashville, TN 37247-6501
(615) 741-0213

Texas
Department of Human Services
P.O. Box 149030
Austin, TX 78714-9030
(512) 450-3050

Utah
Division of Health Care Financing
Utah Department of Health
P.O. Box 16580
Salt Lake City, UT 84116-0580
(801) 538-6478

Vermont
Division of Medicaid
Department of Social Welfare
Vermont Agency of Human Services
103 South Main Street
Waterbury, VT 05671-1102
(802) 241-2880

Virginia
Medical Assistance Services
600 East Broad Street
Suite 1300
Richmond, VA 23219
(804) 786-7933

Washington
Division of Medical Assistance
P.O. Box 45080
Olympia, WA 98504-5080
(206) 753-1777

West Virginia
Office of Medical Services
Bureau of Administration and Finance
Health and Human Resources
Building 6, State Capitol Complex
1900 Washington Street, East
Charleston, WV 25305
(304) 926-1700

Wisconsin
Bureau of Health Care Financing
Division of Health
Department of Health and Social
Services
P.O. Box 309
Madison, WI 53701-0309
(608) 266-2522

Wyoming
Division of Health Care Financing
6101 Yellowstone Road
Cheyenne, WY 82002
(307) 777-7531

State programs for children with special health needs

Alabama
Division of Rehabilitative and Crippled Children's Services
2129 East South Boulevard
Montgomery, AL 36111
(205) 281-8780

Alaska
Handicapped Children's Program
Department of Health & Social Services
1231 Gambell
Anchorage, AK 99501-4627
(907) 274-7626

Arizona
Office of Children's Rehab Services
Arizona Department of Health
1740 West Adams, Room 205
Phoeniz, AZ 85007
(602) 542-1860

Arkansas
Children's Medical Services
Department of Human Services
P.O. Box 1437
Little Rock, AR 72203
(501) 682-2277

California
California Children's Services
State Department of Health
714 P Street, Room 323
Sacramento, CA 94234-7320
(916) 322-2090

Colorado
Handicapped Children's Program
Colorado Department of Health
4210 East 11th Avenue
Denver, CO 80220
(303) 331-8404

Connecticut
Division of Children with Special Health Needs and Child/Adolescent Health
Bureau of Community Health
150 Washington Street
Hartford, CT 06106
(203) 566-2057

Delaware
Child Health/CSHN
Division of Public Health
P.O. Box 637
Dover, DE 19903
(302) 739-4735

District of Columbia
Bureau of Maternal & Child Health
Department of Human Services
1660 L Street, NW, Suite 904
Washington, DC 20036
(202) 673-6665

Florida
Children's Medical Services Program
Department of Health/Rehab Services
Building 5, Room 127
1323 Winewood Boulevard
Tallahassee, FL 32301
(904) 487-2690

Georgia
Children's Medical Services
Department of Human Resources
Division of Public Health
878 Peachtree Street NE, Suite 217
Atlanta, GA 30309
(404) 894-6622

Hawaii
Children with Special Health Care Needs
Hawaii Department of Health
741 Sunset Avenue
Honolulu, HI 96816
(808) 732-3197

Idaho
Children with Special Health Needs
Bureau of Maternal & Child Health
Department of Health/Welfare
450 West State Street
Boise, ID 83720
(208) 334-5963

Illinois
Division of Specialized Care for Children
University of Illinois at Chicago
2815 West Washington, Suite 300
P.O. Box 19481
Springfield, IL 62794-9481
(217) 793-2340

Indiana
Children's Special Health Care Services
Indiana State Board of Health
1330 W. Michigan Street
P.O. Box 1964
Indianapolis, IN 46204-1964
(317) 633-8522

Iowa
Iowa Child Health Specialty Clinic
University of Iowa
Iowa City, IA 52242
(319) 356-1118

Kansas
Children with Special Health Care Needs
Department of Health & Environment
900 SW Jackson, 10th Floor
Topeka, KS 66612-1290
(913) 296-1313

Kentucky
Commission for Handicapped Children
Department of Human Resources
1405 East Burnett Avenue
Louisville, KY 40217
(502) 588-3264

Louisiana
Handicapped Children's Services
Office of Public Health
Department of Health & Hospitals
P.O. Box 60630
New Orleans, LA 70160
(504) 568-5055

Maine
Coordinated Care Service for
Children with Special Health Needs
State House Station 11
151 Capitol Street
Augusta, ME 04333
(207) 289-3311

Maryland
Division of CCS
Department of Health/Mental Hygiene
Mental Retardation/D D Admin
201 W. Preston Street, 4th Floor
Baltimore, MD 21201
(301) 225-5580

Massachusetts
Bureau of Parent/
Child/Adolescent Health
Department of Public Health
150 Tremont Street, 4th Floor
Boston, MA 02111
(617) 727-3372

Michigan
Children's Special Health Care Services
Bureau of Child and Family Services
Michigan Department of Health
P.O. 30195
Lansing, MI 48909
(517) 335-8964

Minnesota
Division of Maternal & Child Health
Minnesota Department of Health
717 Delaware Street SE
P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5166

Missouri
Maternal, Child & Family Health
Missouri Department of Health
1738 E. Elm Street
P.O. Box 570
Jefferson City, MO 65102
(314) 751-6174

Montana
Family and MCH Bureau
Health & Environmental Sciences
Cogswell Building
Helena, MT 59620
(406) 444-4740

Nebraska
Special Services for Children & Adults
Department of Social Services
301 Centennial Hall South, Fifth Floor
Lincoln, NE 68509-5026
(402) 471-9345

Nevada
MCH/CSHCS
Nevada State Health Division
505 East King Street, Room 205
Carson City, NV 89710
(702) 687-4885

New Hampshire
Bureau of Special Medical Services
Division of Public Health Services
6 Hazen Drive
Concord, NH 03301-6527
(603) 271-4596

New Jersey
Special Child Health Services Program
New Jersey Department of Health
CN 364
363 W. State Street
Trenton, NJ 08625-0364
(609) 292-5676

New Mexico
Children's Medical Services
Department of Health & Environment
P.O. Box 968
Santa Fe, NM 87504-0968
(505) 827-2350

New York
Bureau of Child/Adolescent Health
New York Department of Health
Corning Tower Building, Room 780
Empire State Plaza
Albany, NY 12237
(518) 474-2084

North Carolina
Child Health Branch
Environmental Health/Natural Resources
P.O. Box 2091
Raleigh, NC 27802-2091
(919) 733-7437

North Dakota
Crippled Children's Services
Department of Human Services
State Capitol Building, Judicial Wing
Bismarck, ND 58505
(701) 224-2436

Ohio
Division of Maternal & Child Health
Ohio Department of Health
246 North High Street
P.O. Box 118
Columbus, OH 43266-0118
(614) 466-3263

Oklahoma
Children's Medical Services Division
4545 N. Lincoln Blvd., Fourth Floor
Oklahoma City, OK 73103
(405) 557-2539

Palau
Ministry of Health Services
Republic of Palau
MacDonald Memorial Hospital
P.O. Box 100
Koror, Palau 96940

Oregon
Child Development/Rehabilitation Center
Oregon Health Sciences University
P.O. Box 574
Portland, OR 97207
(503) 494-8362

Pennsylvania
Division of Rehabilitative Services
Pennsylvania Department of Health
Room 714
P.O. Box 90
Harrisburg, PA 17108
(717) 783-5436

Puerto Rico
MCH & Children w/Special Health Needs
Department of Health
Commonwealth of Puerto Rico
Call Box 70184
San Juan, PR 00936
(809) 767-0870

Rhode Island
Services for Handicapped Children
Rhode Island Department of Health
Three Capitol Hill
Providence, RI 02908-5098
(401) 277-2312

South Carolina
Division of Children's Health
Health & Environmental Control
2600 Bull Street
Columbia, SC 29201
(803) 737-4056

South Dakota
MCM/CSHS Programs
South Dakota Department of Health
118 W. Capitol
Pierre, SD 57501
(605) 773-3737

Tennessee
Children's Special Services
Department of Health/Environment
100 - 9th Avenue, North
Nashville, TN 37219-5405
(615) 741-7353

Texas
Bureau of Chronically Ill & Disabled Children Services
Texas Department of Health
1100 West 49th Street
Austin, TX 78756-3179
(512) 458-7355

Utah
Children's Special Health Services Bureau
Utah Department of Health
Cannon Building
288 North 1460 West
Salt Lake City, UT 84116-0650
(801) 538-6957

Vermont
Handicapped Children's Services
Vermont Department of Health
1193 North Avenue
P.O. Box 70
Burlington, VT 05401
(802) 863-7338

Virginia
Children's Specialty Services
Virginia Department of Health
109 Governor Street
Richmond, VA 23219
(804) 786-3691

Washington
Children with Special Health Needs
Division of Parent Child Health Services
Department of Health
Mailstop LC-11A
Olympia, WA 98504
(206) 753-0908

West Virginia
Division of Handicapped Children
Department of Health/Human Services
1116 Quarrier Street
Charleston, WV 25301
(304) 348-6330

Wisconsin
Wisconsin Division of Health
P.O. Box 309
Madison, WI 53701
(608) 266-3674

Wyoming
Children's Health Services
Division of Health and Medical Services
Wyoming Department of Health
Hathaway Building
Cheyenne, WY 82002-0710
(307) 777-7941

Parent Training and Information Centers

Parent Training and Information Centers are federally funded organizations in each state that provide training on a variety of issues to parents of children and youth with disabilities.

Alabama
Special Education Action Committee
P.O. Box 161274
3207 International Drive, Suite C
Mobile, AL 36616-2274
(205) 478-1208 Voice & TDD
800-222-7322

Alaska
P.A.R.E.N.T.S. Resource Center
540 International Road, Suite 200
Anchorage, AK 99518
(907) 563-2246 Voice & TDD
800-478-7678

Arizona
Pilot Parent Partnerships
2150 E. Highland Ave., No. 105
Phoenix, AZ 85016
(602) 468-3001 Voice & TDD
800-237-3007

Arkansas
Arkansas Disability Coalition
10002 W. Markham, Suite B7
Little Rock, AR 72205
(501) 221-1330 Voice & TDD

California
DREDF
2212 Sixth Street
Berkeley, CA 94710
(510) 644-2555 (TDD available)

California
Matrix
P.O. Box 6541
San Rafael, CA 94903
(415) 499-3877

California
Parents Helping Parents
535 Race St., Suite 140
San Jose, CA 95126
(408) 288-5010

California
Parents Helping Parents
1801 Vincente Street
San Francisco, CA 94116
(415) 564-0722

California
TASK
100 West Cerritos Ave.
Anaheim, CA 92805-6546
(714) 533-8275

Colorado
PEAK Parent Center, Inc.
6055 Lehman Drive, Suite 101
Colorado Springs, CO 80918
(719) 531-9400 / (719) 531-9403 TDD
800-284-0251

Connecticut
CPAC
5 Church Lane, Suite 4
P.O. Box 579
East Lyme, CT 06333
(203) 739-3089 Voice & TDD
800-445-2722

Delaware
Parent Information Center (PIC)
700 Barksdale Road, Suite 6
Newark, DE 19711
(302) 366-0152 / (302) 366-0178 (TDD)

District of Columbia
COPE
810 Potomac Ave. SE, First Floor Rear
Washington, DC 20003
(202) 543-6046

Florida
Family Network on Disabilities
5510 Gray Street, Suite 220
Tampa, FL 33609
(813) 289-1122 Voice & TDD

Georgia
Parents Educating Parents (PEP)
1851 Ram Runway, Suite 104
College Park, GA 30337-2615
(404) 761-3150 Voice & TDD
800-966-3150

Hawaii
AWARE
200 N. Vineyard Blvd., Suite 310
Honolulu, HI 96817
(808) 536-2280 (Voice & TDD)

Idaho
Idaho Parents Unlimited, Inc.
4696 Overland Road, Suite 478
Boise, ID 83705
(208) 342-5884 Voice & TDD
800-242-4785

Illinois
Designs for Change
6 North Michigan Ave., Suite 1600
Chicago, IL 60602
(312) 857-9292

Illinois
Family Resource Center on Disabilities
20 E. Jackson Blvd., Room 900
Chicago, IL 60604
(312) 939-3513
(312) 939-3519 TDD & TDY

Indiana
IN*SOURCE
833 Northside Blvd., Bldg. 1, Rear
South Bend, IN 46617
(219) 234-7101
800-332-4433 Voice & TDD

Iowa
Iowa Pilot Parents
33 North 12th Street
P.O. Box 1151
Fort Dodge, IA 50501
(515) 576-5870
800-952-4777

Kansas
Families Together, Inc.
1023 Southwest Gage Street
Topeka, KS 66604-1758
(913) 273-6343
800-264-6343

Kentucky
KY-SPIN
2210 Goldsmith Lane, Suite 118
Louisville, KY 40218
(502) 456-0923 or 800-525-7746
800-525-7746

Lousiana
Project PROMPT
4323 Division Street, Suite 110
Metairie, LA 70002-3179
(504) 888-9111
800-766-7736

Maine
Special Needs Parents Info Network
P.O. Box 2067
Augusta, ME 04338-2067
(207) 582-2504
800-870-SPIN Voice & TDD

Maryland
Parents Place of Maryland, Inc.
7257 Parkway Drive, Suite 210
Hanover, MD 21076
(410) 712-0900 Voice & TDD

Massachusetts
Federation for Children
with Special Needs
95 Berkeley St., Suite 104
Boston, MA 02116
(617) 482-2915 (Voice and TTY)
800-331-0688

Michigan
CAUSE
313 S. Washington Square, Suite 040
Lansing, MI 48933
(517) 485-4084 Voice & TDD & TDY
800-221-9105

Michigan
Parents are Experts
23077 Greenfield Road, Suite 205
Southfield, MI 48075-3744
(313) 557-5070 Voice & TDD

Minnesota
PACER Center, Inc.
4826 Chicago Avenue South
Minneapolis, MN 55417-1098
(612) 827-2966
800-537-2237

Mississippi
ADOM
332 New Market Drive
Jackson, MS 39209
(601) 922-3210
800-898-1026

Missouri
Missouri Parents Act
1722W S. Glenstone, Suite 125
Springfield, MO 65804
(417) 882-7434 (TDD)
800-743-7634

Missouri
Missouri Parents Act
8631 Delmar Street, Suite 300
St. Louis, MO 63124
(314) 997-7622 (Voice & TDD)
800-995-3160

Missouri
Missouri Parents Act
1115 East 65th Street
Kansas City, MO 64131
(816) 333-6833 / 333-5685 (TDD)

Montana
Parents Let's Unite for Kids
1500 North 30th St., Room 267
Billings, MT 59101-0298
(406) 657-2055
800-222-7585

Nebraska
NE Parents' Info & Training Center
3610 Dodge St.
Omaha, NE 68131
(402) 346-0525 Voice & TDD
800-284-8520

Nevada
Parent Connection
3380 South Arville, Suite J
Las Vegas, NV 89102
(702) 252-0259, ext. 112

New Hampshire
Parent Information Center
P.O. Box 1422
Concord, NH 03302-1422
(603) 224-7005 (Voice & TDD)
800-232-0986

New Jersey
Statewide Parent Advocacy Network
516 North Ave. East
East Westfield, NJ 07090
(908) 654-7726 Voice & TDD

New Mexico
EPICS Project
P.O. Box 788
Bernalillo, NM 87004
(505) 867-3396
800-767-7320 Voice & TDD

New Mexico
Parents Reaching Out
1127 University Blvd. NE
Albuquerque, NM 87102
(505) 842-9045 Voice & TDD
800-524-5176

New York
Advocates for Children of NY
24-16 Bridge Plaza S.
Long Island City, NY 11101
(718) 729-8866

New York
Parent Network Center
1443 Main Street
Buffalo, NY 14209
(716) 885-1004 / (716) 885-3527 TDD

New York
Resources for Children with Special Needs
200 Park Ave. S., Suite 816
New York, NY 10003
(212) 677-4650

North Carolina
ECAC, Inc.
P.O. Box 16
Davidson, NC 28036
(704) 892-1321
800-962-6817

North Carolina
Families First Coalition, Inc.
300 Enola Road
Morgantown, NC 28655
(704) 433-2662

North Dakota
Pathfinder Family Center
Arrowhead Shopping Center
16th St. and 2nd Ave. SW
Minot, ND 58701
(701) 852-9426 / (701) 852-9436 TDD

Ohio
Child Advocacy Center
1821 Summit Road, Suite 303
Cincinnati, OH 45237
(513) 821-2400

Ohio
OCEHC
1299 Campbell Road, Suite B
Marion, OH 43302
(614) 382-5452 Voice & TDD
800-374-2806

Oklahoma
Parents Reaching Out in OK
1917 S. Harvard Avenue
Oklahoma City, OK 73128
(405) 681-9710
800-PL94-142

Oregon
Oregon COPE Project
999 Locust St. NE, Box B
Salem, OR 97303
(503) 373-7477 Voice & TDD

Pennsylvania
Mentor Parent Program
Route 257, Salina Road
P.O. Box 718
Seneca, PA 16346
(814) 676-8615
800-447-1431

Pennsylvania
Parent Education Network
333 East Seventh Avenue
York, PA 17404
(717) 845-9722 Voice & TDD
800-441-5052 (Spanish)

Pennsylvania
Parents Union for Public Schools
311 S. Juniper St., Suite 602
Philadelphia, PA 19107
(215) 546-1166

Puerto Rico
Parents Training Parents by ANPI
P.O. Box 21301
Rio Piedras, PR 00928-1301
(809) 763-4665 / 765-0345 (Phone & FAX)

Republic of Palau
Palau Parent Network
P.O. Box 1583
Koror, Republic of Palau 76740
(608) 488-3513

Rhode Island
RI Parent Information Network
300 Prospect Street
Pawtucket, RI 02860
(401) 727-4144 / (401) 727-4151 TDD
800-464-3399

South Carolina
PRO-PARENTS
2712 Middleburg Drive, Suite 102
Columbia, SC 29204
(803) 779-3859 Voice & TDD
800-759-4776 Voice & TDD

South Dakota
South Dakota Parent Connection
P.O. Box 84813
Sioux Falls, SD 57118-4813
(605) 335-8844 Voice & TDD
800-640-4553

Tennessee
STEP
1805 Hayes St., Suite 100
Nashville, TN 37203
(615) 327-0294
800-280-STEP

Texas
PATH Project
277 North 18th St., Suite 2
Beaumont, TX 77707-2203
(409) 838-2366 / (409) 838-2363 TDD
800-866-4726

Texas
Project PODER - Texas Fiesta Education
1226 NW 18th Street
San Antonio, TX 78207
(210) 732-8247

Texas
Special Kids, Inc.
P.O. Box 61628
Houston, TX 77208-1628
(713) 643-9576

Utah
Utah PIC
2290 East 4500 S., Suite 110
Salt Lake City, UT 84117
(801) 272-1051
800-468-1160

Vermont
Vermont Parent Information Center
Chace Mill, 1 Mill Street
Burlington, VT 05401
(802) 658-5315 Voice & TDD
800-639-7170

Virginia
PEATC
228 S. Pitt St., Suite 300
Alexandria, VA 22314
(703) 836-2953 (703) 836-3026 (TDD)
800-869-6782

Washington
A Touchstones Program
6721 - 51st Avenue S.
Seattle, WA 98118
(206) 721-0867

Washington
PAVE / STOMP
12208 Pacific Highway SW
Tacoma, WA 98499
(206) 588-1741 Voice & TTY

Washington
Washington PAVE
6316 South 12th
Tacoma, WA 98465
(206) 565-2266 (Voice & TDD)
800-572-7368 Voice & TDD

West Virginia
West Virginia PTI
Colonial Village
104 E. Main Street, Suite 3B
Clarksburg, WV 26301
(304) 624-1436 Voice & TTY

Wisconsin
Parent Education Project
2192 South 60th Street
West Allis, WI 53219
(414) 328-5520
800-231-8382

Wyoming
Wyoming PIC
5 North Lobban
Buffalo, WY 82834
(307) 684-2277 Voice & TDD
800-660-9742

Centers for Independent Living

Most states have more than one Center for Independent Living (CIL). We've listed one per state. Ask for the CIL nearest you.

Alabama
Independent Living Center
206 13th Street, South
Birmingham, AL 35233
(205) 251-2223
TDD: 251-0605

Alaska
Access Alaska, Inc.
3710 Woodland Drive, Suite 900
Anchorage, AK 99517
(907) 248-4777
TDD: 248-4777

Arizona
Bridge to Independent Living
1229 East Washington Street
Phoenix, AZ 85034
(602) 256-2245
TDD: 256-2245

Arkansas
Mainstream Living
1501 South Main, Suite 111
Little Rock, AR 72202
(501) 371-0012
TDD: 372-3575

California
Alternative Training & Learning Center
10070 South Gilbert Street
Anaheim, CA 92804
(714) 991-3662
TDD: none

Colorado
San Luis Valley CIL
P.O. Box 990
Alamosa, CO 81101
(719) 589-9660
TDD: none

Connecticut
Independence Unlimited, Inc.
900 Asylum Avenue, #490
Hartford, CT 06105
(203) 549-1330
TDD: 549-3915

Delaware
Easter Seal Center
61 Corporate Circle
New Castle, DE 19720
(302) 324-4444
TDD: 324-4442

Florida
Broward Independent Living Center, Inc.
1300 South Andrews Avenue
Fort Lauderdale, FL 33335
(305) 467-8572
TDD: 524-0852

Georgia
SW District Independent Living Program
Bill Baker
P.O. Box 1606
Albany, GA 31702
(912) 430-4947
TDD: none

Hawaii
Hawaii CIL
677 Ala Moana Blvd., #118
Honolulu, HI 96813
(808) 537-1941
TDD: 521-4400

Idaho
Dawn Enterprises, Inc.
P.O. Box 388
Blackfoot, ID 83221
(208) 785-5890
TDD: none

Illinois
Impact Center for Independent Living
2735 East Broadway
Alton, IL 62002
(618) 462-1411
TDD: 462-1411

Indiana
Damar Homes, Inc.
P.O. Box 41
Camby, IN 46113
(317) 856-5201
TDD: none

Iowa
Central Iowa Center for Independence
67 Meadow Lane
Cumming, IA 50061
(515) 285-7145
TDD: none

Kansas
Cowley County Developmental Services
P.O. Box 133, Strother Field
Arkansas City, KS 67005
(316) 442-3575
TDD: none

Kentucky
Contact, Inc.
Eric Coffman
103 Bridge Street
Frankfort, KY 40601
(502) 875-5777
TDD: none

Louisiana
New Horizons, Inc.
4030 Wallace Avenue
Shreveport, LA 71108
(318) 635-3652
TDD: 635-3488

Maine
Independent Living Services
331 State Street
Augusta, ME 04330
(207) 622-5434
TDD: 622-5434

Maryland
Center for Independent Living
6305-A Sherwood Road
Baltimore, MD 21239
(301) 377-5900
TDD: 3774591

Massachusetts
Stavros, Inc.
691 South East Street
Amherst, MA 01002
(413) 256-0473
TDD: 256-0473

Michigan
Ann Arbor Center for Independent Living
2568 Packard, Georgetown Mall
Ann Arbor, MI 48104
(313) 971-0277
TDD: 971-0310

Minnesota
Metro Center for Independent Living
1600 University Ave. West, Suite 16
St. Paul, MN 55104
(612) 646-8342
TDD: 646-2515

Mississippi
Jackson Independent Living Center
300 Capers Avenue
Jackson, MS 39203
(601) 961-4140
TDD: 961-4140

Missouri
Services for Independent Living
1301 Vandiver Drive, Suite Q
Columbia, MO 65202
(314) 874-1646
TDD: 874-1646

Montana
Yellowstone Valley CIL
Kim Kennedy
1925 Grand Avenue, Suite 104
Billings, MT 59102
(406) 259-5181
TDD: 259-5181

Nebraska
Goodwill Center for Independent Living
1804 South Eddy
Grand Island, NE 68802
(308) 384-7896
TDD: 384-7896

Nevada
Association for the Handicapped
6200 West Oakey
Las Vegas, NV 89102
(702) 870-7050
TDD: 870-7050

New Hampshire
Granite State
Independent Living Foundation
172 Pembroke Road
Concord, NH 03301
(603) 228-9680
TDD: 228-9680

New Jersey
Success Through IL Experience
1501 Park Avenue
Asbury Park, NJ 07712
(201) 774-4737
TDD: none

New Mexico
C.A.S.A., Inc.
P.O. Box 36916
Albuquerque, NM 87176
(505) 298-7609
TDD: none

New York
Capital District Center for Independence
845 Central Avenue
Albany, NY 12206
(518) 459-6422
TDD: 459-6422

North Carolina
Programs for Accessible Living
1012 South Kings Drive
Doctor's Bldg., G-2
Charlotte, NC 28283
(704) 375-3977
TDD: 375-3977

North Dakota
Fraser Hall
Sandra Leyland
711 South University Drive
Fargo, ND 58103
(701) 232-3301
TDD: none

Ohio
Tri-County Independent Living Center
680 East Market Street, Suite 205
Akron, OH 44304
(216) 762-0007
TDD: 762-7429

Oklahoma
Caddo County Independent Living
Center
132 East Broadway Street, #208
Anadarko, OK 73005
(405) 247-7331
TDD: 247-7331

Oregon
Central Oregon Resources for IL
43 Northwest Greeley
Bend, OR 97701
(503) 388-8103
TDD: none

Pennsylvania
Resources for
Living Independently Center
One Winding Way, Suite 108
Philadelphia, PA 19131
(215) 581-0666
TDD: 581-0664

Rhode Island
Blackstone Valley Center ILP
115 Manton Street
Pawntucket, RI 02861
(401) 727-0150
TDD: none

South Carolina
Independent Living Program
1410 Boston Avenue, P.O. Box 15
West Columbia, SC 29171
(803) 822-5314
TDD: none

South Dakota
Opportunities for Independent Living
P.O. Box 1571
Aberdeen, SD 57402
(605) 622-2298
TDD: none

Tennessee
Memphis Center for Independent Living
163 North Angelus
Memphis, TN 38104
(901) 726-6404
TDD: 726-6404

Texas
Panhandle Action CIL Skills
3608 South Washington
Amarillo, TX 79110
(806) 352-1500
TDD: 352-8630

Utah
OPTIONS for Independence
1095 North Main
Logan, UT 84321
(801) 753-5353
TDD: 753-5353

Vermont
Center for Independent Living
174 River Street
Montpelier, VT 05602
(802) 229-0501
TDD: 229-0501

Virginia
Appalachian Independence Center
230 Charwood Drive
Abingdon, VA 24210
(703) 628-2979
TDD: 628-4931

Washington
Resource Center for the Handicapped
20150 - 45th Avenue, Northeast
Seattle, WA 98155
(206) 362-2273
TDD: none

West Virginia
Mountain State Centers for IL
914 - 1/2 Fifth Avenue
Huntington, WV 25701
(304) 525-3324
TDD: 525-3324

Wisconsin
Southeast Wisconsin CIL
6222 West Capitol Drive
Milwaukee, WI 53216
(414) 438-5622
TDD: 438-5627

Wyoming
Independent Living Rehabilitation
246 South Center, Suite 16
Casper, WY 82601
(307) 266-6956
TDD: 266-6956

District of Columbia
Center for Independent Living
1400 Florida Avenue, Northeast, #3
Washington, DC 20002
(202) 388-0033
TDD: 388-0033

Samoa
Center for Independent Living
Government of American Samoa
Pago Pago, AS 96799
(684) 633-1804
TDD: none

Puerto Rico
Centro de Vida Independiente
Apartado 1681
Hato Rey, PR 00919
(809) 758-0424
TDD: none

Virgin Islands
Association for IL
P.O. Box 3305
Charlotte Amalie, St. Thomas, VI 00803
(809) 775-9740
TDD: none

Vocational Rehabilitation Programs

Alabama
Division of Rehabilitation and
Crippled Children Service
Department of Education
2129 East South Boulevard
Post Office Box 11586
Montgomery, AL 36111
205-281-8780

Alaska
Division of Vocational Rehabilitation
Department of Education
801 West 10th Street, Suite 200
Juneau, AK 99801
907-465-2814

American Samoa
Vocational Rehabilitation
American Samoa Government
Post Office Box 3492
Pago Pago, American Samoa 96799
684-633-1805

Arizona
Rehabilitation Services Bureau
Department of Economic Security
1789 West Jefferson, 2nd Floor N.W.
Phoenix, AZ 85007
602-542-3332

Arkansas
Div. of Rehabilitation Services
Department of Human Services
7th and Main Sts.
300 Donaghey Plaza, North
Post Office Box 3781
Little Rock, AR 72203
501-682-6708

California
Department of Rehabilitation
Health and Welfare Agency
830 K Street Mall
Sacramento, CA 95814
916-445-3971

Colorado
Division of Rehabilitation
Department of Social Services
4th Floor, 1575 Sherman Street
Denver, CO 80203
303-866-5196

Connecticut
Bureau of Rehabilitation Services
Dept. of Human Services
10 Griffin Road North
Windsor, CT 06195
203-298-2000

Delaware
Div. of Vocational Rehabilitation
Department of Labor
321 East 11th Street
Wilmington, DE 19801
302-577-2850

District Of Columbia
Vocational Rehabilitation Services
Admin.
Department of Human Services
605 G Street, N.W.
Washington, DC 20001
202-727-3227

Federated States of Micronesia
Voc. Rehabilitation Coordinator
Post Office Box 400
Moen, Truk State
Federated States of Micronesia 96942
691-330-2320

Florida
Div. of Vocational Rehabilitation
Dept. of Labor and Employment Security
1709-A Mahan Drive
Tallahassee, FL 32399
904-488-6210

Georgia
Division of Rehabilitation Services
Department of Human Resources
Room 706, 878 Peachtree Street, N.E.
Atlanta, GA 30309
404-894-6670

Guam
Department of Vocational Rehabilitation
Room B201, 122 Harmon Plaza
Harmon Industrial Park, Guam 96911
671-646-9468

Hawaii
Vocational Rehabilitation and
Services for the Blind
Department of Human Services
Room 615, 1000 Bishop Street
Honolulu, HI 96813
808-548-4769

Idaho
Div. of Vocational Rehabilitation
State Board for Voc. Education
Room 150, 650 West State
Boise, ID 83720
208-334-3390

Illinois
Department of Rehabilitation Services
623 East Adams Street
Post Office Box 19429
Springfield, IL 62794
217-785-0218

Indiana
Div. of Vocational Rehabilitation
Dept. of Human Services
402 West Washington Street
Post Office Box 7083
Indianapolis, IN 46207
317-232-1319

Iowa
Vocational Rehabilitation Services
Department of Public Instruction
510 E. 12th Street
Des Moines, IA 50319
515-281-4154

Kansas
Rehabilitation Services
Social and Rehabilitation Services
1st Floor, 300 S.W. Oakley
Topeka, KS 66606
913-296-3911

Kentucky
Dept. of Voc. Rehabilitation
Department of Education
Capital Plaza Tower, 9th Fl.
500 Metro Street
Frankfort, KY 40601
502-564-4566

Louisiana
Div. of Vocational Rehabilitation
Office of Human Development
8225 Florida Boulevard
Post Office Box 94371
Baton Rouge, LA 70804
504-925-4131

Maine
Bureau of Rehabilitation Services
Department of Health and Welfare
35 Anthony Avenue
Augusta, ME 04333
207-626-5300

Maryland
Division of Rehabilitation Services
State Department of Education
2301 Argonne Drive
Baltimore, MD 21218
301-554-3276

Massachusetts
Rehabilitation Commission
Fort Point Place
27-43 Wormwood Street
Boston, MA 02210
617-727-2172

Michigan
Rehabilitation Services
Department of Education
4th Floor, 101 Pine Street
Post Office Box 30010
Lansing, MI 48909
517-373-3391

Minnesota
Div. of Vocational Rehabilitation
Department of Jobs and Training
5th Fl., 390 North Robert Street
St. Paul, MN 55101
612-296-1822

Mississippi
Rehabilitation Services
Post Office Box 1698
Jackson, MS 39215
601-354-0287

Missouri
Div. of Vocational Rehabilitation
State Department of Education
2401 East McCarty Street
Jefferson City, MO 65101
314-751-3251

Montana
Rehabilitative Services Division
Social and Rehabilitative Services
Post Office Box 4210
Helena, MT 59601
406-444-2590

Nebraska
Division of Rehabilitation Services
Department of Education
6th Floor, 301 Centennial Mall
Post Office Box 94987
Lincoln, NE 68509
402-471-3645

Nevada
Rehabilitation Division
Department of Human Resources
State Capitol Complex
505 East King Street
Carson City, NV 89710
702-687-4440

New Hampshire
Division of Vocational Rehabilitation
State Department of Education
Bldg. JB, 78 Regional Drive
Concord, NH 03301
603-271-3471

New Jersey
Vocational Rehabilitation Services
Department of Labor and Industry
611 Labor and Industry Bldg.
CN 398
Trenton, NJ 08625
609-292-5987

New Mexico
Div. of Vocational Rehabilitation
Department of Education
435 St. Michael's Dr., Bldg. D
Santa Fe, NM 87505
505-827-3511

New York
Vocational Educational Services for
Individuals with Disabilities
Rm. 1907, 99 Washington Ave.
Albany, NY 12234
518-474-2714

North Carolina
Div. of Vocational Rehabilitation Services
Dept. of Human Resources
800 Ruggles
Post Office Box 26053
Raleigh, NC 27611
919-733-3364

North Dakota
Department of Vocational Rehabilitation
State Board of Social Services
400 East Broadway Avenue, Suite 303
Bismarck, ND 58501
701-224-3999

Northern Marianas
Vocational Rehabilitation Service
Post Office Box 1521-CK
Commonwealth of the Northern
Marianas
Saipan, Mariana Islands 96950

Ohio
Rehabilitation Services Commission
400 East Campus View Blvd.
Columbus, OH 43235
614-438-1210

Oklahoma
Department of Human Services
Rehabilitative and Visual Services
Post Office Box 25352
Oklahoma City, OK 73125
405-424-4311

Oregon
Vocational Rehabilitation Div.
Department of Human Resources
500 Summer Street, N.E.
Salem, OR 97310
503-945-6201

Pennsylvania
Bur. of Vocational Rehabilitation
Department of Labor and Industry
Rm. 1300, 7th and Forster Streets
Harrisburg, PA 17120
717-787-5244

Puerto Rico
Rehabilitacion Vocacional
Division de Rehabilitacion Vocacional
Departmento de Sevicios Sociales
Apartado 1118
Hato Rey, PR 00919
809-724-3120

Rhode Island
Vocational Rehabilitation
Department of Human Services
40 Fountain Street
Providence, RI 02903
401-421-7005

South Carolina
Vocational Rehabilitation Dept.
1410 Boston Avenue
Post Office Box 15
W. Columbia, SC 29171
803-822-4300

South Dakota
Div. of Rehabilitation Services
E. Highway 34
c/o 500 E. Capitol
Pierre, SD 57501
605-773-3195

Tennessee
Div. of Vocational Rehabilitation
Department of Human Services
15th Floor, 400 Deaderick Street
Nashville, TN 37219
615-741-2019

Texas
Texas Rehabilitation Commission
Rm. 7102, 4900 N. Lamar
Austin, TX 78751
512-483-4001

Utah
Office of Rehabilitation
State Board of Education
250 East Fifth South
Salt Lake City, UT 84111
801-538-7530

Vernont
Vocational Rehabilitation Div.
Social and Rehabilitation Services
103 South Main Street
Waterbury, VT 05676
802-241-2186

Virgin Islands
Disabilities and Rehabilitation Services
c/o Dept. of Human Services
Barbel Plaza South
Charlotte Amalie
St. Thomas, VI 00801
809-774-2835

Virginia
Department of Rehabilitative Services
State Board of Vocational Rehabilitation
Post Office Box 11045
Richmond, VA 23230
804-367-0318

Washington
Div. of Vocational Rehabilitation
Dept. of Social and Health Services
P.O. Box 45340
Olympia, WA 98504
206-438-8009

West Virginia
Division of Rehabilitation Services
State Board of Rehabilitation
State Capitol
Charleston, WV 25305
304-766-4601

Wisconsin
Division of Vocational Rehabilitation
Department of Health and Social Services
Room 830, 1 West Wilson Street
Post Office Box 7852
Madison, WI 53707
608-266-5466

Wyoming
Division of Vocational Rehabilitation
Department of Health and Social Services
1100 Herschler Building
Cheyenne, WY 82002
307-777-7389

Client Assistance Projects

Alabama
Client Assistance Program
2129 East South Boulevard
P.O. Box 11586
Montgomery, AL 36111-0586

Alaska
CAP Director
ASIST
2900 Boniface Parkway, No. 100
Anchorage, AK 99504-3195

Americam Samoa
Client Assistance Program
and Protection and Advocacy
P.O. Box 3937
Pago Pago, AS 96799

Arizona
Center for Law in the Public Interest
3208 East Fort Lowell, Suite 106
Tuscon, AZ 85716

Arkansas
Advocacy Services, Inc.
Evergreen Place, Suite 201
1100 North University
Little Rock, AR 72207

California
Client Assistance Program
California Department of Rehabilitation
830 K Street Mall, Room 220
Sacramento, CA 95814

Colorado
Client Assistance Program
The Legal Center
455 Sherman Street, Suite 130
Denver, CO 80203

Connecticut
Office of Protection and Advocacy for
Handicapped and Developmentally
Disabled Persons
60 Weston Street
Hartford, CT 06120-1551

Delaware
Client Assistance Program
United Cerebral Palsy, Inc.
13 S.W. Front Street, Suite 105
Milford, DE 19963

District of Columbia
Client Assistance Program
Rehabilitation Services Administration
605 G Street NW, Room 1101
Washington, DC 20001

Client Assistance Program
I.P.A.C.H.I.
4455 Connecticut Ave. NW, Suite B100
Washington, DC 20008

Florida
Advocacy Center for Persons with
Disabilities
2671 Executive Center, Circle West
Webster Building, Suite 100
Tallahassee, FL 32301-5024

Georgia
Client Assistance Program
Division of Rehabilitation Services
878 Peachtree St. NE, Suite 708
Atlanta, GA 30309

Guam
Parent Agencies Network
130 Rehabilitation Center Street
Koro, Guam 96911

Hawaii
Protection and Advocacy Agency
1580 Makaloa Street, Suite 1060
Honolulu, HI 96814

Idaho
Co-Ad, Inc.
4477 Emerald, Suite B-100
Boise, ID 83706

Illinois
Client Assistance Project
100 N. First Street, 1st Floor
Springfield, IL 62702

Indiana
Indiana Advocacy Services
850 N. Meridian St., Suite 2-C
Indianapolis, IN 46204

Iowa
Division on Persons with Disabilities
Lucas State Office Building
Des Moines, IA 50319

Kansas
Client Assistance Program
Biddle Building, 2nd Floor
2700 W. 6th Street
Topeka, KS 66606

Kentucky
Director
Client Assistance Program
923 Capitol Plaza Tower
Frankfort, KY 40601

Louisiana
Advocacy Center for
the Elderly and Disabled
210 O'Keefe, Suite 700
New Orleans, LA 70112

Maine
CARES, Inc.
4-C Winter Street
August, ME 04330

Maryland
Client Assistance Program
State Department of Education
Division of Vocational Rehabilitation
300 W. Preston St., Suite 205
Baltimore, MD 21201

Massachusetts
Client Assistance Program
Office on Disability
One Ashburton Place, Room 303
Boston, MA 02108

Michigan
Client Assistance Program
Department of Rehabilitation Services
P.O. Box 30008
Lansing, MI 48909

Commission for the Blind
201 N. Washington Square, 2nd Floor
P.O. Box 30015
Lansing, MI 48909

Minnesota
CAP Project Coordinator
Disability Law Center
430 First Ave. N., Suite 300
Minneapolis, MN 55401-1780

Mississippi
Client Assistance Program
Blind and Visually Impaired
Easter Seal Society
3226 N. State Street
Jackson, MS 39216

Missouri
Protection and Advocacy Services, Inc.
925 S. Country Club Drive, Unit B-1
Jefferson City, MO 65109

Montana
Montana Advocacy Program
316 N. Park, Room 211
P.O. Box 1680
Helena, MT 59624

Nebraska
Division of Rehabilitation Services
Nebraska Department of Education
301 Centennial Mall South
Lincoln, NE 68509

Nevada
Client Assistance Program
1755 East Plumb Lane, No. 128
Reno, NV 89502

New Hampshire
CAP Ombudsman
Commission on Disability
57 Regional Drive
Concord, NH 03301-8506

New Jersey
Department of the Public Advocate
Office of Advocacy for the DD
Hughes Justic Complex, CN 850
Trenton, NJ 08625

New Mexico
Protection and Advocacy System
1720 Louisiana Blvd. NE, Suite 204
Albuquerque, NM 87110

New York
Client Assistance Program
Commission on Quality of Care for the
Mentally Disabled
99 Washington Ave., Suite 1002
Albany, NY 12210

North Carolina
Client Assistance Program
Vocational Rehabilitation Services
P.O. Box 26053
Raleigh, NC 27611

North Dakota
Client Assistance Program
400 East Broadway, Suite 303
Bismark, ND 58501-4038

North Marianas Island
P & A Administrator
Karidat
P.O. Box 745
Saipan, CM 96950

Ohio
Client Assistance Program
Office of Advocacy for People with
Disabilities
30 E. Broad Street, Room 1201
Columbus, OH 43266-0400

Oklahoma
Client Assistance Program
Office of Handicapped Concerns
4300 N. Lincoln Boulevard, Suite 200
Oklahoma City, OK 73105

Oregon
Disabilities Commission
1257 Ferry Street, SE
Salem, OR 97310

Pennsylvania
Client Assistance Program
1650 Arch Street, Suite 2310
Philadelphia, PA 19103

Client Assistance Program
Medical Center East
211 N. Whitfield, Suite 215
Pittsburg, PA 15206

Puerto Rico
Ombudsman for the Disabled
P.O. Box 5163
Hato Rey, PR 00919-5163

Rhode Island
Client Assistance Program
Protection and Advocacy System
151 Broadway
Providence, RI 02903

South Carolina
Division of Ombudsman and Citizen Services
P.O. Box 11369
Columbia, SC 29211

South Dakota
Client Assistance Program
South Dakota Advocacy Services
221 South Central Avenue
Pierre, SD 57501

Tennessee
Tennessee P & A, Inc.
P.O. Box 121257
Nashville, TN 37212

Texas
Advocacy, Inc.
7800 Shoal Creek Blvd., Suite 171-E
Austin, TX 78757

Utah
Client Assistance Program
Legal Center for People with Disabilities
455 East 400 South, Suite 201
Salt Lake City, UT 84101

Vermont
Client Assistance Program
Ladd Hall
103 S. Main Street
Waterbury, VT 05676

Virginia
Department of Rights for Virginians with Disabilities
101 N. 14th Street, 17th Floor
Richmond, VA 23219

Virgin Islands
Client Assistance Program
Virgin Islands Advocacy Agency
7A Whim Street, Suite 2
Fredericksted, VI 00840

Washington
Client Assistance Program
P.O. Box 22510
Seattle, WA 98122

West Virginia
Client Assistance Program
West Virginia Advocates
1524 Kanawha Blvd., East
Charleston, WV 25311

Wisconsin
Commission for People with Disabilities
1 W. Wilson Street, Room 558
P.O. Box 7850
Madison, WI 53707-7850

Wyoming
Client Assistance Program
Protection and Advocacy System, Inc.
2424 Pioneer Avenue, Suite 101
Cheyenne, WY 82001

Bibliography

Beckett, J. (1989) *Health care financing: A guide for families.* Iowa City, IA: National Maternal and Child Health Resource Center, University of Iowa.

Chesler, M., and Andersen, B. (1987) "Chronically ill adolescents as health care consumers." *Chronically Ill Children: Policy and Practice.* Edited by John W. Hagen and Craig R. Barclay. University of Michigan Center for Human Growth and Development, Ann Arbor, MI. 103-120.

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Shapland, C., and Schoeller, K. (1993) *Speak Up for Health: A Handbook for Parents.* PACER Center, Inc., Minneapolis, MN.